An Occupational Therapist Knows...

**BIPOLAR DISORDER**

The Basic Fact Sheet

Bipolar disorder, or manic depression, is a serious mental disorder that causes extreme shift in mood, energy, and functioning.

**FACTS & FIGURES**

- It affects 2.3 million Americans (1.2% of the population).
- 7 out of 10 people with bipolar disorder receive one misdiagnosis.
- 30% of people with untreated bipolar disorder commit suicide.
- An equal number of men and women develop the illness and it is found among all ages, races, ethnic groups, and social classes.

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Types of Bipolar Disorder

**BIPOLAR 1**
Severe manic and depressive episodes

**BIPOLAR 2**
Alternation of Hypomania and Depression

Rapid Cycling: 4 or more mood episodes in a year

**Not Otherwise Specified:**
Doesn’t meet criteria for BP1 or BP2, but symptoms exist

**Cyclothymia:**
Emotional Ups and Downs, but not as severe as Bp1 or Bp2

Mania is an abnormally elated mental state, typically characterized by feelings of euphoria, lack of inhibitions, racing thoughts, diminished need for sleep, talkativeness, risk taking, and irritability. In extreme cases, mania can induce hallucinations and other psychotic symptoms.

Depression: The persistent feeling of sadness and loss of interest that can lead to a range of emotional and physical condition including the inability to sleep or concentrate on tasks, changes in appetite, decreased energy level, and thoughts of suicide.

Info found at NIMH, DBSA, PsychCentral, Helpguide, Mayo Clinic

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**Diagnosis Facts**
- People with Bi-Polar who receive at least 1 misdiagnosis: 70%
- People who receive correct diagnosis within 3 years: 25%
- Chance that a child will be bipolar if 1 parent is: 66%
- Chance when both parents are bipolar: 23%

**Signs & Symptoms**

**MANIA**
- Inflated self-esteem or grandiosity
- Unusual talkativeness
- Racing thoughts
- Distractibility
- Agitation
- Unusual behavior with high potential for painful consequences

**DEPRESSION**
- Depressed mood most of the day, nearly every day, such as feeling sad, empty, hopeless or tearful
- Can appear as irritability
- Markedly reduced interest or feeling no pleasure
- Feeling worthless
- Decreased ability to concentrate, or Indecisiveness
- Significant weight loss when not dieting, weight gain, or decrease or increase in appetite
- Either insomnia or sleeping excessively
- Recurrent thoughts of death or suicide, or suicide planning or attempt

**Fact**
25% of those diagnosed with bipolar disorder commit suicide

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Bipolar is like being on a roller coaster ride. Sometimes you can predict drop offs and others you just have to hang on because the next turn sends you into an unexpected spiral.

Sometimes you are laughing and throwing your hands in the air and then other times you are clinging, simply holding on for dear life screaming it the top of your lungs.

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BIPOLAR DISORDERS

Nothing new, just a new name... FOR MANIC-DEPRESSIVE

Then 5,000  Number of years ago that manic-depressive disorder was documented

Now 5.7M  adult Americans affected by bipolar disorder (or 2.6% of population) today

25 average age for beginning of bipolar disorder

50/50 men and women get bipolar equally...

3X...but women are 3 times more likely to experience rapid cycling with B.D.

6 bipolar disorder is 6th leading cause of disability in the world.

8 in 10 Number of those with B.D. who think about suicide at least once in their life.

9.2 Number of years subtracted from your lifespan if you have B.D.

1 in 12 Number of those in general population who will think about suicide in their life.

A Worldwide Condition

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When was Bipolar Disorder first described?

Bipolar disorder as we know it has been described in clinical medicine for more than 5000 years.

The ancient Greek physician and philosopher Aretaeus of Cappadocia wrote about a group of his patients who had extreme mood variants one day to the next.

In the 1900s German psychiatrist Emil Kraepelin studied the disorder and coined the term "manic-depressive insanity" to describe it.

The terms "manic-depressive illness" and "bipolar disorder" are comparatively recent, and date back to the 1950s and 1980s (DSM III) respectively.

How is a person diagnosed with Bipolar Disorder?

The diagnosis of bipolar disorder is based on a careful longitudinal history from the patient and ideally from family members since many patients will deny manic or hypomanic episodes, considering them to be periods of optimal functioning.

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Lifetime Suicide Rates
- 9% for Major Depressive Disorder
- 10% for Schizophrenia
- 20% for Bipolar Disorder

3 women have BD for every 2 men

Manic depression became bipolar disorder in 1980

3X more days spent in depression than...

...days spent in mania or hypomania

80-90% success rates for lithium in the 70s...
in acute mania are now 40-50%

Sources: NAMI, HCUP, WHO, CDC

by: Rhona Finkel

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BIPOLAR DISORDER

THE HIGHS
- Over-excitement
- Restlessness
- High Sex-Drive
- More impulsive
- High Sex drive
- Making unrealistic plans
- Becoming more impulsive
- Drug and alcohol abuse
- Poor concentration

SYMPTOMS

Two "Poles" of Bipolar Disorder

THE LOWS
- Sadness
- Insomnia
- Thoughts of suicide or attempting suicide
- Uncontrollable crying
- Changes in Appetite
- Loss of energy
- Trouble concentrating
- Trouble making decisions

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Based on the results of the evaluation, a person may be diagnosed with one of the following categories of bipolar disorder:

**Bipolar I Disorder**
Presence of one or more manic or mixed (a mixture of manic and depressive symptoms in the same episode) episodes. Individuals will almost always have one or more major depressive episodes.

**Bipolar II Disorder**
Presence of one or more major depressive episodes accompanied by at least one hypomanic episode.

**Cyclothymic Disorder**
Presence of numerous hypomanic episodes and episodes of depression — but never a full manic episode, major depressive episode, or a mixed episode. For a diagnosis of cyclothymic disorder, symptoms have to last two years or more (one year in children and adolescents). During that time, symptoms can never be absent for more than two months.

Suicide rates are higher in Bipolar II compared to Bipolar I.

Mixed episodes are the most common subtype of bipolar disorder.

80% The estimated heritability of liability to bipolar disorder is approx. 80%.

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The Facts About

Bipolar Disorder

6th leading cause of disability world-wide

Most expensive mental health care diagnosis in the US

50% of BD people have substance abuse issues

Average cost of hospital stay for depression (2008*): $4700

Average cost of hospital stay for BD (2008*): $5600

Hospitalization rate of bipolar patients is 39.1% in the US, which is . . . .

. . . . more than the 4.5% for all other behavioral health care diagnoses

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**Manic episode:**
- Elated, “high,” “up”
- Increased energy, craving activity
- Racing thoughts and ideas
- Feeling “super” powers

**Depressive episode:**
- Empty, “low,” “down”
- Zapped, little or no energy
- Trouble concentrating
- Negative thoughts

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An estimated 5.7 million Americans are affected.

It affects all races, ethnic groups and socio-economic backgrounds equally.

The median age of onset is 25 years old.

It can manifest in early childhood or as late as age 50. However, it usually starts in the teen years.

It is the 6th leading cause of disability in the world.

3 out of 10 people with the illness will attempt suicide during their lives.

Over 2/3 of people with the illness have at least one close relative with the illness.

The expected life span is reduced by about 9 years for those who are affected.

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Self-Management Strategies Used by ‘High Functioning’ Individuals with Bipolar Disorder: From Research to Clinical Practice

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Introduction: Bipolar disorder (BD) is a complex mental illness that results in substantial costs, both at a personal and societal level. Research into BD has been driven by a strongly medical model conception, with a focus upon pathology and dysfunction. Little research to date has focused upon strategies used to maintain or regain wellness in BD. Here, we present results from a qualitative study of self-management strategies used by a Canadian sample of ‘high-functioning’ individuals with BD. The aims of the present paper are two-fold: (1) To provide a description of the self-management strategies identified as effective by this sample of high functioning individuals and 2) to explore these results from a clinical perspective.

Methods: High functioning (determined as a score of either 1 or 2 on the objectively-rated Multidimensional Scale of Independent Functioning) individuals with BD type I or II (N = 33) completed quantitative scales to assess depression, mania, psychosocial functioning and quality of life, and underwent either an individual interview or focus group about the self-management strategies they used to maintain or regain wellness.

Results: The specific self-management strategies that individuals enacted are contained within the following categories: (1) sleep, diet, rest and exercise; (2) ongoing monitoring; (3) reflective and meditative practices; (4) understanding BD and educating others; (5) connecting to others and (6) enacting a plan. These strategies are discussed in the

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context of current treatment interventions and research findings, offering clinicians a broad range of potential techniques or tools to assist with their efforts to support individuals with BD in maintaining or regaining wellness.

Conclusions: The strategies adopted by a sample of people coping well with their BD show remarkable overlap with the targets of existing adjunctive psychosocial interventions for BD. The clinician can use this information to motivate clients to engage with such strategies. The present findings also serve to remind the clinician of significant individual differences in the personal meaning and concrete application of superficially similar strategies. Copyright © 2010 John Wiley & Sons, Ltd.

Key Practitioner Message:
- People who function well despite a significant history of bipolar disorder identify a range of strategies that are critical in their wellbeing.
- Key wellbeing strategies are: (1) managing sleep, diet, rest and exercise; (2) ongoing monitoring; (3) reflective and meditative practices; (4) understanding BD and educating others; (5) connecting to others and (6) enacting a plan.
- These strategies constitute ‘tips from the experts’ that can be offered to clients to increase hopefulness and improve engagement with psychosocial interventions.
- Clinicians will be familiar with these strategies as elements of existing psychosocial interventions—the present qualitative data provides significant cross-validation of the importance of these behaviours.

Keywords: Bipolar Disorder, Self-Management, Wellness, Clinician, Qualitative

INTRODUCTION

Bipolar disorder (BD) is a chronic psychiatric condition typically characterized by recurring episodes of depression and mania (a distinct period of abnormally elevated, expansive or irritable mood) or hypomania (the subsyndromal counterpart to mania) (Goodwin & Jamison, 2007). Marked variability can occur between individuals with BD in terms of the type, number and length of episodes experienced, the severity and type of symptoms encountered, and the degree of recovery attained between mood episodes.

Outcome in BD has traditionally been determined by the assessment of objectively measured clinical information, such as rates of relapse or degree of symptom reduction on clinician-rated assessment scales. More recently, however, there has been increasing emphasis upon the need for additional forms of assessment to measure treatment outcome or recovery. For example, Keck (2004) has suggested that ‘Functional outcomes are more meaningful measures of response to treatment for BD than are scores on various psychiatric rating scales’. Psychosocial functioning describes a person’s ability to perform the tasks of daily life and to engage in mutual relationships with other people in ways that are gratifying to the individual and others, and that meet the needs of the community in which the person lives. Most (e.g., Altshuler et al., 2006; Kauer-Sant’Anna, Bond, Lam, & Yatham, 2009; Miklowitz et al., 2007a) but not all (Michalak, Yatham, Kolesar, & Lam, 2006) existing research into psychosocial functioning in BD has used quantitative research methods. Of these quantitative studies, the majority have examined psychosocial functioning in individuals who are symptomatic or experiencing a mood episode; scant research has examined functioning in interepisode or well individuals (e.g., Leidy, Palmer, Murray, Robb, & Revicki, 1998; Maina et al., 2007).

To our knowledge, only one previous qualitative study has examined the self-management strategies used by people to stay well with BD (Russell & Browne, 2005). The results of the study identified two main themes—a ‘stay well’ concept and ‘strategies to stay well’. Common strategies used to stay well included: acceptance of diagnosis, mind-
fulness education, identifying triggers, recognition of warning signs, sleep and stress management, making lifestyle changes, treatment access support and stay well plans. While the study provided some useful initial data, it also had some methodological limitations. For example, participants in the study self-identified as having maintained wellness for a 2-year period with no concomitant objective assessment and no clinical information collected.

We set out to expand upon this body of literature via a qualitative study examining the self-management strategies used by high functioning individuals\(^1\) with BD. To avoid some of the limitations of the Russell and Browne (2005) study and our own previous qualitative research (Michalak, Murray, Young, & Lam, 2007), we committed to: use a carefully screened sample of participants, collect detailed quantitative data on symptoms, psychosocial functioning and quality of life (QoL) and utilize rigorous qualitative analysis techniques. Our objectives for the present paper are to: (1) describe the categories of self-management strategies identified as effective by a sample of individuals with BD who are ‘high functioning’ and (2) to explore clinical implications of these findings by synthesizing them with existing quantitative knowledge about strategies in adjunctive psychosocial interventions for BD.

**Participants**

The study was completed by a total of 33 participants with BD (63%, \(n = 20\) female, age mean = 41.1, \(SD = 13.3\)) (Table 1). The sample was drawn from residents of British Columbia, Canada.

**Recruitment**

Calls for participation were distributed via a number of channels, including: newsletters from the Mood Disorders Association of British Columbia, the Canadian Mental Health Association and other community mental health organizations, community newspapers, networking, public talks and education events and a range of websites. The advertisement invited people with a diagnosis of BD type I or II, be 19 years or older, fluent in English, have a global score of less than 3 on the MSIF and not be in an episode of illness that would render participation in a qualitative interview or focus group difficult (e.g., severe depression or florid mania, based on clinical judgment). It is important to note, however, that individuals who were experiencing a mood episode but were still functioning well remained eligible for participation as we hypothesized that people who were maintaining their functional status despite high burden of symptoms could have important insights into self-management strategies for BD.

1Our research also samples from people who are not functioning well with their BD—a comparison of strategies amongst high versus low functioning individuals will be the focus of a future report.
Participants were offered a choice of individual or group formats for the qualitative interviews. Interviews were conducted by one of the three primary investigators (S.H., M.S., E.M.), all of whom had significant expertise in qualitative research methods, lasted between 60–90 minutes and took place in participants’ homes, at the university and/or over the telephone. A semi-structured interview guide was used to ensure that all participants were asked similar questions (e.g., what strategies have you found most helpful in managing BD? How do friends, family and co-workers affect your ability to stay well?). All interviews were audio recorded and transcribed verbatim. As is common in qualitative traditions, data collection and data analysis happened concurrently (Maxwell, 2005; Richards, 2005), and thematic analysis (Braun & Clark, 2005) was used to compare, contrast and categorize the data into themes (both within and across transcripts). The data were coded, organized and re-organized several times as categories were developed, and an exploration of the relationships between and within subcategories led to the development of an initial coding framework and preliminary themes. The research team met to evaluate the initial coding framework and to synthesize the categories and concepts into themes. Data were coded according to these themes, whereupon coded data segments were again reviewed to determine their fit with each theme. QSR International (Americas) Inc., Cambridge, MA, USA (NVivoQSR) (Bazeley, 2007), a qualitative software programme, was used to manage the data and facilitate data analysis. Analytic meetings were held to discuss and monitor coding consistency to address the analytic validity of identified themes (Morse &

| Table 1. Demographic and clinical characteristics (N = 32) |
|---------------------------------|------------------|
| Variable                        | Score            |
| Sex                             |                  |
| Females                         | 20 (62.5%)       |
| Male                            | 12 (37.5%)       |
| Type                            |                  |
| Bipolar I                       | 25 (78.1%)       |
| Bipolar II                      | 7 (21.9%)        |
| Mean age (SD)                   | 41.1 years old (13.3) |
| Mean # of depressive episodes (SD)| 14.79 (15.94)   |
| Mean # of manic episodes (SD)   | 8.3 (18.40)      |
| Mean # of hospitalizations (SD) | 3 (4.64)         |
| Mean HAM-D score (SD)           | 8.03 (9.20)      |
| Mean YMRS score (SD)            | 2.45 (3.00)      |
| Mean Q-LES-Q % max score (SD)   |                  |
| Physical health domain          | 68.69 (19.88)    |
| General feeling domain          | 70.96 (15.43)    |
| Work domain                     | 82.73 (13.76)    |
| Household duties domain         | 72.00 (23.04)    |
| School/Course domain            | 74.44 (25.18)    |
| Leisure time activities domain  | 77.77 (16.46)    |
| Mean social domain              | 78.96 (16.44)    |
| Overall-general domain          | 73.54 (20.20)    |
| Satisfaction with medication (median [range]) | 3 (3) |
| Overall life satisfaction (median [range]) | 4 (4) |
| Have a job                      | 16 (51.6%)       |
| Work for self                   | 14 (45.2%)       |
| Volunteer work                  | 13 (41.9%)       |
| Mean SAS score (SD)             | 1.76 (0.44)      |
| Mean SAS T-score (SD)           | 55.31 (13.46)    |

HAM-D = Hamilton Depression Rating Scale. YMRS = Young Mania Rating Scale. Q-LES-Q = Quality of Life Enjoyment and Satisfaction Questionnaire. SAS = Social Adjustment Scale. SD = standard deviation.
Richards, 2002). In addition, the research team met to ensure that the findings were internally consistent and supported by the data from the participants’ interviews (Sandelowski, 2000). Therefore, emergent themes are supported by direct quotes from the participants as to enable readers to evaluate the interpretations.

RESULTS

The self-management strategies presented here comprise actions, routines and processes that participants initiated to cope with BD and get on with the job of living. The importance of these strategies is that they arise from participants’ experiences and are considered effective by people with BD who are functioning well. The strategies illustrate the beginnings of a self-management approach to living with a chronic mental illness. The strategies are: (1) sleep, rest, diet and exercise; (2) ongoing monitoring; (3) reflective and meditative practices; (4) understanding BD and educating others; (5) connecting with others and (6) enacting a plan.

Sleep, Rest, Diet and Exercise

Participants identified getting sufficient and regular sleep as one of the most important strategies for maintaining or regaining wellness. Their description of sleep as a lynchpin to health indicates the critical role that sleep plays for people with BD. Some participants emphasized the benefits of sleep and naps on a routine basis whereas others described the association between sleep and rest to symptoms of mania and depression. One person explains:

I guess another boundary that I set is sleep. That I make sure that I get to bed by 10:30–11:00 every night. And a routine is really important. So I think those kinds of things. And I wouldn’t say that I’ve been absolutely symptom-free but managing, learning to self-monitor.

Waking rest was also useful to many participants and usually involved lying down or watching TV. This strategy enabled people to meet social and work responsibilities. This focus upon sleep/rest hygiene is hardly novel but its importance lies in the regularity of the practice, which was also true for participants’ dietary choices.

Attention to diet and nutrition as a self-management strategy involved choosing healthy foods, eating regularly scheduled meals and taking vitamin supplements. Incorporating these actions into routines gave structure to participants’ lives and helped many of them feel balanced and in control. The ability to eat well and regularly was associated with stability whereas more erratic patterns or excesses reflected shifts in mood, as Robyn explains.

When I’m down I don’t eat heavy foods. I eat lighter foods, I eat more meals, smaller meals, higher energy meals, quicker to digest meals. The worst thing when you’re depressed is to eat high fat foods, fried foods, and sit there in a big puddle of fat, with your stomach bringing you down even more.

Most participants identified adhering to a self-defined good diet and proper nutrition as part of functioning well. They monitored the overuse of potentially mood-altering substances such as caffeine and sugar. Although not strictly part of diet, several participants described either avoiding alcohol or decreasing the amount they drank, and eliminating the use of recreational drugs such as marijuana.

Exercise was a popular wellness strategy that participants used and they emphasized the importance of finding the right type of exercise. Participants described a wide variety of activities including: Tai Chi, dance, yoga, exercise routines, walking, snowboarding and swimming. Two participants indicated that exercise occurs through their work; one person taught dance classes 5 days a week and the other person referred to many years of teaching yoga. Exercise often involved activities outdoors and the location itself had a salutary health effect. The emphasis on outdoor activities is not surprising given the many options in British Columbia, the temperate climate of Vancouver and the active lifestyle that is culturally and socially encouraged.

One of the older participants described the how regular exercise affects her wellness:

Walking by the sea is something that I try and do three . . . you know a few times a week . . . I went out just for half an hour this evening to catch the sunset, so walked fifteen minutes west and then came back. I consider that a very important part of my overall balance, is the walking.

One of the younger participants recounted numerous outdoor activities she did, and again, regularity and setting played a big role.

A fair amount of cardio, I used to run the marathons to help keep my mania down. Now I just
do cardio at the gym and I mix it up, do different ones. I still do some running, do some cross training, the elliptical, whatever you call it . . . I do the aerobic cycle . . . at least three times a week . . . for at least a half an hour and about forty-five minutes of weights.

Overall, participants were acutely aware of the impact that the right sleep, rest, diet and exercise choices had on their lives. These strategies are inexpensive, within one's control and reflect common sense. As one participant concluded 'Exercise regularly, get enough sleep, and eat health balanced diet . . . It sounds really boring and it's in every magazine but being active really works for me.'

Ongoing Monitoring

This set of self-management strategies reflected participants' strong motivation to stay well and assume responsibility for their wellness. Participants described the importance of learning to pay close attention to their moods and involvement in activities, in order to judge when to make changes. Understanding personal behavioural patterns and warning signs requires self-awareness and was a more common strategy among individuals who had lived with BD longer than those more recently diagnosed. Self-monitoring and being vigilant ('I'm always looking at my mood') prompted participants to adjust their activities to avoid getting overwhelmed: 'I keep myself in check . . . so I try to just keep myself calm and always think before I act.' For example, individuals would spread tasks out over the week, cancel social engagements if necessary and maintain some unscheduled time. Several participants spoke of being less critical of themselves for past actions and recognizing the importance of self-monitoring. Max describes changing his expectations.

I will just become more diligent about exercise, eating right, more sleep, and trying to . . . I guess reassign priorities. So that if I have a lot on my plate of things I wanted to get done, get rid of a few of them, one way or another, get rid of a few of them. So you that can focus on what needs to be done and accept the fact that you're not going to get as much done as you would like to.

The description of symptoms or the recognition that something was wrong varied across the participant group. Some individuals sensed physical changes (‘It's like a motor slowly turning off in my body’), whereas others observed their activity level for warning signs: 'If there are over 9 things on my “To-do” list, that's a danger sign . . . if there is no “To-do” list, that means I'm heading for depression.' The use of prescription medications and the ability to monitor the dose or initiate as-needed medications played a key role in maintaining wellness for the majority of participants. A few individuals remained well without taking medications; however, many more described making small changes after recognizing an increase in their symptoms. This is reflected in one participant's comment, 'I've learned my early warning signs and I make minor adjustments.' Some participants consulted with their psychiatrist, either in person or by telephone, before making any medication changes. Regular self-monitoring and adjustment requires considerable effort but has its rewards, as one individual describes:

To me it's an ongoing basis where it's like a ship that's always righting itself, you know. Or when you're driving, you're sort of correcting as you're trying to drive in a straight line. So those were the things that I see, and then I make minor adjustments and hopefully I don't have to make major adjustments because I've been always making these corrections.

Ongoing monitoring added to the knowledge that participants obtained about the disorder through other means, such as psychoeducation (PE).

Reflective and Meditative Practices

Participants reported using various reflective and meditative practices to help them maintain their wellness. These ranged from practices such as Tai Chi, yoga and meditation to the use of regular journaling, inspirational reading and praying. Rather than relying on any one practice, participants typically drew from several actions that were successful in the past. For example, one participant stated that her main strategies were to: keep a journal, meditate and listen to calming music. Journaling was a popular strategy with many participants; one individual described its benefits this way:

When I feel bad, then I write everything down. My emotions, and what it's directed to, whether it be a person or frustration at work, I have to be able to get it out, because I haven't really got anybody
that I can actually talk to about this, and if I can write everything down, then I can get everything that I need to out, cause if I’m talking to somebody, then the facial expressions, their voice intonation, their interrupting, whatever it might be, then I can’t get everything out. So, with being able to do that, then it’s a sense of relief.

Participants who engaged in Tai Chi and yoga cited the benefits of regular practice, which for some included their roles as teachers. For Zoe, the commitment to Tai Chi practice along with self-monitoring strategies led to a ‘zone of stability’ that allowed her to manage BD well despite experiencing symptoms. Another eastern-based practice involved Buddhist-inspired watchfulness that emphasized ‘compassion and loving kindness’, taking a slightly different route than cognitive behavioural therapy (CBT) to reframe negative thoughts.

In addition to these practices, creative activities such as painting encouraged some participants to focus, stay well and gain insight into their actions. Another wellness self-management strategy was educating themselves and people involved in their lives about BD.

**Understanding BD and Educating Others**

Participants learned about BD through a variety of methods that included reading books and newsletters, finding information on the Internet, attending groups, charting their unique cycles and stressors, and talking to healthcare practitioners. Participants read books that described the disorder and also texts that combined factual information with narratives such as *An Unquiet Mind* by Kay Redfield Jamieson (Jamison, 1995) and *A Brilliant Madness* by Patty Duke (Duke & Hochman, 1992). One participant described learning about BD, and the benefits of doing so, in this way:

> Reading lots of books, on the Internet, the mental health counsellor gave me some good resources. Eventually I ended up being the chairperson of the bipolar disorder group, so I’m just making sure everybody else had resources, and also other people would also feed back information to me.

Some participants attended PE groups organized by the Mood Disorders Association of British Columbia or through local hospitals to obtain initial information or keep current with new developments. Most individuals described a process of obtaining information that required considerable self-initiative. There were strong opinions about the benefits and drawbacks of groups as a means to learn more about BD; some people found that the groups became less structured over time and were somewhat depressing. Some participants preferred individual sessions and recounted having supportive doctors and other healthcare practitioners who provided information about BD.

Many participants found that different forms of therapy, whether it was skills-based CBT or insight-oriented psychotherapy, helped them learn how to reduce stress, monitor mood changes and generally gain knowledge about how to live well with BD. Zoe identified a pivotal therapy experience in this way:

> There’s a regular bipolar group which I’ve been attending since 1998. So I’m just thrilled. They’re very open. They encourage the interaction between your family doctor, your family, your employer and so on and so forth. And if you don’t want to do that, that’s fine too. If you need help doing that, they provide that help.

Participants shared what they learned about BD with family members and friends who were supportive. Thus, a spouse/partner of a person with BD learned the warning signs of mania and depression and encouraged their loved one to use strategies that helped that person stay well. Spouses/partners helped the person with BD to identify activity pattern changes or alterations from their usual habits that could signal mood changes. Robyn explains:

> I think my husband is really important because he will notice a depressive episode coming on before I will and he can tell by my body language. He says I walk differently. I carry myself differently and there is a look in my forehead and my eyebrows. He picks it out before I do... He makes me aware of it and then I will just become more diligent about exercise, eating right, more sleep, and trying to... I guess, reassign priorities.

It is not surprising that participants chose to connect with and seek support from family and friends who became knowledgeable about BD.

**Connecting with Others**

This self-management strategy involved maintaining social connections with friends, seeking out
professional support, and for some people, doing volunteer work. Participants who had developed non-judgmental friends described the importance of socializing and having fun, of finding a balance between solitary and social time. One person described meeting with a core group of friends for coffee, a routine that provided considerable support and stability as he recovered from a manic episode. Lydia explains the benefits of connecting with friends:

_Hanging out with friends is a big one, just have that down time. Just being yourself with people you’re comfortable with, probably helps me keep well._

Psychiatrists, nurses and general practitioners were among the healthcare professionals whose services participants sought out as a means of staying well. This connection occurred through mood disorders support groups and one-to-one sessions. The value of a quality relationship, built on respect and collaboration, was emphasized by most participants who possessed one, and was desired by those did not have this type of support. One participant who lives outside of metropolitan Vancouver illustrated the role her doctor plays in her life.

_I see my psychiatrist one or two times a year. And he’s available by email or phone anytime I feel that it’s needed. So I have that as a resource. . . . He also treats me with more respect, for my level of intellect and level of understanding and my decision about my health care, than probably any other psychiatrist I’ve had. So that means more than me than having someone local._

Volunteering was a useful means of connecting with others that many participants initiated. They described getting involved in charity work as a way to put their own issues into perspective. Some participants discussed volunteering with organizations that provided services for people with mental health problems and how they could use their own experiences to help others in an earlier phase of recovery. Alternatively, participants volunteered in a variety of capacities with community groups that were unrelated to mental health. Lydia sums up the benefits of volunteer work.

_Well, I had periods where I was really depressed and, and very dark, and not involved in community, not involved with others. I was really kind of, you know, just in my own space in my own world feeling very isolated, and very self-analyzing. So what I’ve noticed is that when I have a bit more outward kind of motivation and movement and being involved in the world in helping other people or even just giving things away or giving of my time, and energy, that’s really helpful in terms of keeping balanced in my own life._

Connecting with friends, family and doing volunteer work is not unique to people with BD; the difference is the impact that these social interactions had on maintaining wellness especially during times of stress.

**Enacting a Plan**

Enacting a plan occurred when participants recognized an impending manic or depressive episode and usually involved others to assist them. The plan could be an informal understanding between family members or friends about how to support the person with BD when wellness was compromised. Or the plan could be a detailed document that was developed over time and used to guide decisions. One example of the latter is the Wellness Recovery Action Plan (WRAP), popularized by Copeland (2000) as a self-management tool for recovery. The WRAP involves identifying triggers and stressors that threaten wellness, making a list of trusted individuals to call on for support, describing activities and strategies to maintain wellness and detailing the kinds of circumstances that prompt initiating a crisis plan. Robyn describes using the WRAP to judge the seriousness of an impending depressive episode.

_If I have three days in a row where I’ve just kind of felt down and blue, then I pull out my wellness plan and I look and it usually will kind of help me out in that time. If that’s not working and I actually end up into ‘signs and symptoms,’ and those are listed, the little red flags like, ‘I don’t care.’ That’s a huge one with me. If I’ve gotten to the point where I am saying ‘I don’t care,’ then I’ve kind of lost that hope. And that’s getting into the signs and symptoms; still able to manage it at home but into signs and symptoms. When I am talking about death and dying, those are the kind of symptoms that we’re looking at getting into a hospital then._

While this excerpt describes the exacerbation of illness, Robyn stated ‘I have never had to use my
actual crisis plan because I do my maintenance and it seems like the more well I am, the easier it is to be well.’ This analysis supports the development and use of self-management strategies that are suited to each person that can serve as the sort of ‘maintenance’ that will facilitate living well with BD.

**DISCUSSION**

A number of themes arose in our novel qualitative investigation of management strategies employed by high functioning people with BD. Our aim in this final section is to optimize the clinical utility of these findings by integrating it with existing knowledge about what works in adjunctive psychosocial interventions for BD. There is growing evidence that psychosocial interventions improve outcomes in BD (Miklowitz, 2008), and we show below how our qualitative findings are consonant with, and offer an elaborated personal narrative of, the core elements in evidence-based treatments.

**Sleep, Rest, Diet and Exercise**

Maintaining sleep, diet and exercise routines were cited as a lynchpin to maintaining wellness by many of the sample. Although the biological underpinnings of BD are not well understood, there is consensus that instability of circadian rhythms is a significant pathway in the development and course of the condition, and the link between sleep and BD is well-established (Murray & Harvey, 2010). Importantly, circadian rhythms and sleep are modifiable by non-pharmacological means; consequently, their management is a core element of a variety of psychosocial treatment interventions for BD (e.g., Miklowitz, Goodwin, Bauer, & Geddes, 2008) and a component of consensus treatment guidelines (e.g., Yatham et al., 2006).

Frank and others (Ehlers, Frank, & Kupfer, 1988; Frank, 2007; Healy & Waterhouse, 1995) have argued that rhythmic features of the social environment (such as the timing of sleep, eating and exercise) are significant components of human circadian entrainment, and disruption of these habits may challenge the circadian clock. Frank and colleagues have developed a psychosocial treatment intervention based on this understanding known as ‘Interpersonal and Social Rhythm Therapy’ (IPSRT; Frank, 2007), a combination of a largely behavioural therapies aimed at helping patients maintain stability in their social rhythms and traditional interpersonal psychotherapy IRSPT (Frank, 2007). IPSRT has proven effective in two treatment studies (Frank et al., 2005; Miklowitz et al., 2007b). A key element of IPSRT is measurement of social rhythm stability via a scale known as the Social Rhythm Metric (SRM). The latest version of this self-report diary instrument, the SRM-II-5 (Frank, 2005), assesses the regularity of the time at which the individual (1) gets out of bed, (2) has first contact with another person, (3) starts work, school or housework, (4) has dinner and (5) goes to bed. As well as assessing social cues such as these, the clinician and client with BD can explore other interactions, such as: What is the relationship between social rhythmicity and daily mood? What role do others play in the person’s social rhythmicity? What barriers to regularizing social rhythms can be identified and resolved?

Poor sleep quality is a major barrier to social rhythm stability and a primary target of IPSRT (Frank, 2005). Sleep disturbances are also a significant detriment to QoL in BD and a major clinical focus in their own right (Michalak et al., 2007). Sleep should be routinely assessed in individuals diagnosed with BD. This assessment can be simplified to a two-step process. First, the clinician can assess for the most common presenting symptoms of sleep disorders (insomnia and excessive daytime sleepiness). Second, the clinician can ask about additional symptoms such as snoring, observed apnea and abnormal sleep behaviours. Overall sleep quality can be usefully measured on the valid and reliable Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989).

Insomnia in individuals with serious mental illness is often addressed with medication, and many patients’ timely use of small doses of benzodiazepines or sedating antipsychotics is an effective part of manic relapse prevention (Russell, 2005). However, there is evidence that the psychosocial techniques effective for sleep disturbance in non-psychiatric populations are also effective in individuals with comorbid psychiatric disorders, and these should be offered as a first-line treatment (Biancosino et al., 2006; Smith, Huang, & Manber, 2005; Smith & Perlis, 2006). These interventions are generically termed CBT for insomnia (CBT-I).

Key components of CBT-I are stimulus control, sleep restriction, relaxation training, cognitive approaches and sleep hygiene education (see Morin & Espie, 2003; Perlis, Smith, Jungquist, & Posner, 2005). The overarching aim of CBT-I is to develop good sleep habits, which both facilitates...
As monitoring is also a key element of (Printz, Kahn, Carpenter, & Docherty, 2000). Mood management of the disorder (Goodwin, 2003; Sachs, lines suggest that daily mood monitoring should well with BD. Indeed, published treatment guide-

What additional light do our interviews throw on this intervention? First, participants highlighted the key subjective distinction between sleep as a symptom of disorder, and sleep management as a stay-well strategy. The notion of ‘waking rest’ as a fruitful strategy is a second finding from our interviews that is not yet recognized in CBT-I. Finally, our analysis of the interviews highlighted a subjective link between sleep and daily exercise routines, consistent with contemporary models of sleep and alertness as complementary processes across the 24-hour day (Dijk & Franken, 2005). The importance of working to identify the exercise that suits the individual in context was highlighted by participants. The observation that people had tried various forms until finding a strategy that worked is critical information for clinicians as they support their clients in identifying and implementing useful routines.

Ongoing Monitoring

Participants described the importance of regularly monitoring their moods in an effort to stay well with BD. Indeed, published treatment guidelines suggest that daily mood monitoring should be incorporated into the routine clinical management of the disorder (Goodwin, 2003; Sachs, Printz, Kahn, Carpenter, & Docherty, 2000). Mood monitoring is also a key element of PE (Bauer & McBride, 1996; Bauer, McBride, Chase, Sachs, & Shea, 1998) and cognitive behavioural (Basco & Rush, 1996; Lam, Jones, Hayward, & Brill, 1999) treatment interventions for BD.

Mood monitoring could influence outcome for clients with BD through a variety of mechanisms. First, regular monitoring of mood could provide an ‘early warning system’ for imminent relapse, allowing intervention to stop progression into a full-blown mood episode. A number of studies have shown that relapse, especially into mania, is preceded by idiosyncratic but identifiable and consistent prodromal symptoms in the 2–4 weeks prior to full relapse (see e.g. Lam & Wong, 1997) and that these symptoms can be used to trigger early inter-

 awareness of their own idiosyncratic version of BD, which complemented the general knowledge of BD acquired through PE.

**Reflective and Meditative Practices**

Participants reported using a variety of reflective and meditative practices to help maintain wellness, including Tai Chi, yoga, meditation, journaling, inspirational reading, exploring their spirituality and praying. Kilbourne and colleagues (2007) have provided data on the use of complementary and alternative medicines in a sample of 435 individuals with BD within a large urban mental health facility in the USA, finding that over half of their participants used prayer, spiritual healing or meditation to help manage their condition. There is as yet very little data relating to the efficacy of practices such as a yoga and massage in the treatment of the condition (Andreescu et al., 2008). The related approach of mindfulness CBT has received initial support as an adjunctive intervention (Williams et al., 2008), and our qualitative data suggest that such approaches may have face validity for many people with BD.

**Understanding BD and Educating Others**

Although education about BD was critical for many of the sample, educational routes came in a number of guises, including entirely self-directed education (through reading, the Internet, etc.), support and education though peer support groups and formal PE groups delivered via specialist mood disorders centres.

PE at its most basic level is the process of imparting information to the individual with the disorder. A range of manual-based, standardized PE interventions (designed either for individual or group delivery) have been developed, although they all tend to have similar treatment goals and use similar techniques (e.g., Bauer Life goals [Bauer & McBride, 1996]). Typical treatment goals include: preventing relapse and recurrence, reducing the number and severity of symptoms, decreasing suicide risk, enhancing medication adherence and improving psychosocial functioning and QoL. Frequently used techniques include: education about BD and its treatment (for both the client and their significant others), promoting early detection of symptoms, encouraging lifestyle regulation (e.g., regulation of sleep-wakes cycles and social routines), enhancing self-monitoring and improving stress management skills.

The most convincing evidence to date for the effectiveness of group PE for BD is provided by Colom and colleagues (2003) who randomized euthymic patients (N = 120) who had been in remission for at least 6 months and were receiving standard pharmacological treatment to either 21 sessions of group PE or an equal number of unstructured group meetings. During the acute treatment phase of the study, significantly more patients in the control group (60%) fulfilled criteria for recurrence (of hypomania, mania, mixed state or depression) than did patients in the intervention group (38%). At the end of the 2-year follow-up phase, 92% of the control group had experienced a recurrence, compared to 67% of the psychoeducated group. Of course, delivering a 21-session, manualized PE intervention may not be pragmatic or feasible for many clinicians. The strength of the evidence for PE in BD, however, does point to the importance of providing education about this complex psychiatric condition where possible. Our experience warns that individual differences are important in response to PE: only some participants in the current study were highly supportive of the formalized group PE model. Others preferred not to attend group sessions, relying instead on written resources in hard copy or on the Internet. These resources are both prolific and of varied quality. People managing BD in rural or remote areas may not have access to PE groups and may need additional direction to identify good quality educational materials and resources.

**Connecting with Others**

Deficits in social support are reliably associated with poor outcome in BD (e.g., Goldberg & Burdick, 2008; Mueller et al., 2006; Ritsner, Gibel, & Ratner, 2006). Indeed, whether researchers have studied rates of divorce, marital conflict, social isolation, core confidant relationships or satisfaction with social support in individuals diagnosed with BD, there is evidence that these individuals describe dissatisfaction and problems with their relationships. Alternatively, there is evidence that adequate social support is protective in BD (Johnson et al., 1999; Johnson et al., 2000) and can counteract psychological vulnerability (Murray et al., 2007). Connecting meaningfully with other people was important to many of this sample of high functioning individuals. Once again, however, there was no single model for meaningful social support, with participants citing the importance of family, friends, work
colleagues, support group members and healthcare professionals.

There is a growing literature on the role of family-focused interventions in the treatment of BD (e.g., Miklowitz & Goldstein, 1997) and data is available from some key clinical trials. For example, in one trial of medication plus family-focused therapy (FFT, a 9-month, 21-session intervention consisting of PE, communication training and problem-solving skills training), participants in the FFT protocol showed longer healthy intervals prior to relapse that participants receiving medication and brief PE (Miklowitz, George, Richards, Simoneau, & Suddath, 2003). However, there is insufficient data on family-orientated treatments for BD to permit meta-analyses according to Cochrane criteria (Justo, Soares, & Calil, 2007).

Another potential point of social leverage exists in the relationship between the individual with BD and their treating clinician. The power of this relationship can be maximized by adopting a strongly collaborative stance (Berk, Berk, & Castle, 2004; Crosini & Wedding, 2005). Key elements of a collaborative therapeutic relationship are: (1) the clinician is warm, directive and concerned, a problem-solver applying a coping model, (2) the client is active in determining the specific targets of therapy, while the clinician is expert in proposing pathways to achieve these goals, (3) the client and clinician therefore work as a collaborative team, (4) the therapeutic emphasis is on measurable changes outside the therapy room and (5) the therapeutic goals are supported by learning principles (e.g., change as incremental). In practice, a collaborative therapeutic atmosphere can be generated by asking clients to give their opinions about treatment, and what they think might be effective on the basis of past experience. A collaborative treatment approach also means that sometimes the client’s, rather than the clinician’s, treatment choice is followed. As noted by Basco and Rush (1996), the potential for short-term difficulties this generates is likely to be outweighed by the long-term impacts on the working relationship. Our data strongly supports this therapeutic prescription—all participants either had or desired, a professional relationship in which their views were respected and in which they were treated as collaborators in BD management.

**Enacting a Plan**

Participants talked about a variety of plans they had in place for when early warning signs of an impending episode were detected, ranging from an informal understanding with family members or friends, through to more formal plans such as the WRAP (Copeland, 2000).

Research has shown that most people with BD can both recognize their prodromes and appreciate the utility of early warnings of relapse (Lam & Wong, 2005). Importantly, there is evidence that, although prodromes vary between individuals they may be relatively stable within-person. Across studies, the most common early warning signs of mania are decreased need for sleep, increased activities/energy, being more sociable, racing thoughts, having increased self-worth, senses being sharper and increased optimism. The most common early warning signs of depressive relapse are loss of interest in activities or people, not being able to put worries or anxieties aside, interrupted sleep and feeling sad or wanting to cry. Central goals of psychosocial interventions, then, are to help the individual develop expertise about their own early warning signs. The individual can then be encouraged to respond to early warning signs by activating a pre-arranged personal relapse prevention plan. The rationale behind relapse prevention plans is that the individual commits to following the specific behavioural steps of the plan (developed with the therapist when euthymic) at a time when their mood state might be a barrier to calm problem-solving. Key elements of a relapse prevention plan include names and contact details of the primary clinician and others in the person’s support network. More elaborate plans can include specific behavioural steps for managing prodromes of depression and mania/hypomania (for more discussion, see Basco, 2006; Basco & Rush, 1996). A number of points about relapse prevention plans are worth noting. First, managing BD requires a team approach that includes, but is not limited to, the primary clinician. Specified social supports also play an important role in relapse prevention plans, and participants in our study highlighted that this is premised on thinking about how and to whom to reveal one’s diagnosis. Second, much of the work in adjunctive psychosocial interventions for BD focuses on developing the client’s expertise about their own version of the disorder—a relapse prevention plan is largely a structured document summarizing this expertise.

**SUMMARY**

Our novel qualitative investigation of self-management strategies used by people who are coping well with BD generated two incremental advances. First, we were able to give voice to
the positive well-being strategies that are found effective by people who are diagnosed with BD, and indeed have a significant mental illness history. This is important data because it provides a hopeful narrative, critical for clinicians and their clients as they approach the challenge of managing BD. Second, by integrating qualitative data with existing quantitative knowledge about effective psychosocial treatment strategies we were able to provide a more contextualized set of cognitive behavioural guidelines for clinicians to apply in their therapeutic collaborations.

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A Review of Evidence-Based Therapeutic Interventions for Bipolar Disorder

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Bipolar disorder is a complex disability that presents substantial challenges for diagnosis and treatment. Recent research shows that there is a significant need for adjunctive psychotherapy to supplement and optimize the benefits of medication. Researchers and clinicians recognize that quality of life outcomes are at least as important as clinical outcomes to successful treatment of bipolar disorder. A growing body of literature indicates that psychotherapeutic interventions benefit bipolar clients and have the potential to significantly improve their psychosocial functioning and decrease the substantial social costs of the illness. In this article we examine psychoeducational interventions along with three evidence-based interventions that address the complexity of bipolar disorder.

An increasingly sophisticated understanding of the neurobiology and pathophysiology of bipolar disorder indicates a more complex constellation of symptoms than was previously recognized. Phillips and Frank (2006) recently concluded that the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association [APA], 2000) "fails to reflect the multisystem presentation of bipolar disorder" (p. 1135); they recommended that the upcoming fifth edition of the DSM reflect a symptom-based definition of bipolar disorder as a multisystemic disorder involving disturbances in physical, psychological, and social domains. It is now recognized that because "individuals with bipolar disorder suffer from a marked disruption in sleep rhythms and social relations" (p. 1135), it cannot be narrowly defined as a disorder characterized by episodic mood disturbances.

Psychiatrists now recognize that bipolar disorder is not a variant of unipolar depression or other mood disorders (Phillips & Frank, 2006) but a complex condition that often requires aggressive multimodal treatment (Leahy, 2007). This complexity often makes it difficult to diagnose and treat, and the chronic

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symptomology and impairment experienced by individuals with the disorder significantly impacts their physical health and overall quality of life (Culver, Arnow, & Ketter, 2007).

The following review of four evidence-based practices (psychoeducation, cognitive behavioral therapy, family-focused therapy, and interpersonal and social rhythm therapy) provides an overview of the nature of bipolar disorder and the diagnostic and treatment challenges it presents. The primary intent is to highlight the need for adjunct psychotherapy to enhance pharmacological treatments for individuals with bipolar disorder.

**BIPOLAR DISORDER: A BIGGER PICTURE**

The DSM estimates the lifetime prevalence of bipolar I disorders (recurrent episodes of depression and mania) as 0.4–1.6% and bipolar II disorders (milder mania that alternates with depressive moods) as 0.4–0.5% (APA, 2000; Merikangas et al., 2007). It is the sixth most common cause of disability in the United States, the fifth leading cause of disability among 15–44-year-olds globally, and the ninth leading cause of years lost due to death or disability worldwide (World Health Organization [WHO], 2001). The lifetime rate for completed suicide among people with bipolar disorder has been estimated to be 60 times higher than that for the general population (Baldessarini, Pompili, & Tondo, 2006). Woods (2000) estimated the societal cost of bipolar disorder at $45 billion annually in the United States alone. These statistics highlight the significance of bipolar disorder as a public health concern.

**A Complex Disability**

The DSM alone cannot convey the devastating effects that bipolar disorder has on a patient’s quality of life. The conventional view that bipolar disorder has a better prognosis than schizophrenia has been challenged due to the large percentage of patients who exhibit chronic residual affective symptoms and unpredictable mood cycling and therefore experience significant impairment in psychosocial functioning (Zaretsky, Rizvi, & Parikh, 2007). Murray and Michalak (2007) stated that “if bipolar disorder develops in a woman at the age of 25, she may lose 9 years in life expectancy (due to medical problems), 14 years of productivity, and 12 years of good health” (p. 24).

As a consequence of their illness, the quality of life for individuals with bipolar disorder is characterized by lower wages, higher unemployment, work absenteeism and disability, marked interpersonal relationship instability and higher divorce rates, lower levels of educational attainment, and higher rates of arrest, hospitalization, and premature death compared to the general population (Depp, Davis, Mittal, Patterson, & Jeste, 2006).
Bipolar Disorder Treatment Challenges

Interpersonal problems, life events, and lack of stress-management skills are characteristic of bipolar disorder, and these stressors worsen the course and outcomes of the illness (Basco, Ladd, Myers, & Tyler, 2007). Typically, pharmacological treatments are essential for managing bipolar disorder (Miklowitz & Otto, 2006); however, medication alone is often inadequate to restore and maintain physical health and quality of life. For example, one study found that as many as 60% of patients never regain full occupational and social functioning (MacQueen, Young, & Joffe, 2001). Research increasingly supports the theory that a combination of pharmacotherapy and psychotherapy significantly improves long-term outcomes for these individuals (Culver et al., 2007; Leahy, 2007; Miklowitz & Otto, 2006; Rizvi & Zaretsky, 2007); therefore, an integrated care approach to managing bipolar disorder gives therapists an opportunity to significantly improve functioning and quality of life for clients and their families.

The therapeutic objectives for managing bipolar disorder to maximize healthy functioning include treatment of acute manic and depressive episodes, reducing the risk of suicide, relapse prevention (a lifelong risk), and symptom awareness and control (Culver et al., 2007). Culver et al. stressed that counseling interventions should address these significant treatment challenges for the disorder in the life context of individual patients and their families.

RATIONALE FOR THERAPEUTIC INTERVENTIONS

According to Culver, Arnow, and Ketter (2007), medications used to treat bipolar disorder have been inadequate for a large proportion of these patients, who report persisting depressive or manic symptoms after a year on medications. The primary treatment challenge is nonadherence to medication regimens: approximately 60% of bipolar clients take less than 30% of their medication as prescribed (Culver, Arnow, and Ketter, 2007; Rizvi & Zaretsky, 2007).

Since medication alone appears to be ineffective, therapeutic interventions for bipolar disorder, such as psychoeducation and other counseling modalities, have become increasingly evidenced-based and integrated into treatment. Rizvi and Zaretsky (2007), along with Miklowitz and Otto (2006), demonstrated that psychoeducation, cognitive behavioral therapy, family-focused therapy, and interpersonal and social rhythm therapy are effective adjunct treatments (in addition to medication). Murray and Michalak (2007) concurred that psychosocial interventions in conjunction with medications showed promise of improving both clinical and quality of life outcomes and family functioning.

Clinical Outcomes

The primary clinical goals of therapeutic interventions in patients with
bipolar disorder include psychoeducation about the nature and treatment of the disorder, symptom reduction, episode prevention, medication adherence, increased recognition of early symptomology, facilitation of early medical intervention, and strategies for relapse prevention (Culver, Arnow, & Ketter, 2007). Culver, Arnow, and Ketter also reported that therapeutic interventions can provide clients with the knowledge, skills, and tools to effectively manage their disorder. Psychotherapy, when used to supplement and support medication regimens, may allow patients to decrease or eliminate reliance on antidepressant medications, which are thought to increase the risk of mood destabilization and acute manic or mixed episodes (Zaretsky, Rizvi, & Parikh, 2007).

The four interventions examined here have yielded positive results. Psychoeducation in conjunction with medication has been shown not only to increase the client's knowledge but also to delay relapse as well as reducing the number of relapses (Colom et al., 2003). Cognitive behavioral therapy with medication also yielded fewer relapses and improved adherence to medication and psychosocial functioning (Lam & Gale, 2000). Although family-focused therapy showed no benefit in reducing risk of relapse (Rea et al., 2003), it was found that clients had fewer relapses than those receiving just individual therapy. Interpersonal and social rhythm therapy showed limited but positive results; it was not shown to be superior to control treatments but showed evidence that suicidal risk decreased as well as the person's social rhythm (Frank et al., 2005; Rucci et al., 2002).

Quality of Life Outcomes

In addition to clinical outcomes, the quality of life of individuals with bipolar disorder is commanding increased attention. Some patients function poorly despite having relatively few symptoms; others function well despite having relatively severe symptoms (Murray & Michalak, 2007). Similarly, there is dissonance between improvement in symptoms and improvement in quality of life measures in response to treatment, "with the latter lagging substantially behind the former" (p. 24). When patients assess the success of their treatment, they focus on more than clinical symptoms, and optimal treatment benefit will result when therapists adopt a holistic approach. Murray and Michalak predicted that "it may be in the area of functional outcomes that psychosocial interventions make their strongest contribution" (p. 24).

The WHO describes quality of life as "the individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" (Murray & Michalak, p. 24). There has been little quantitative research into quality of life for people with bipolar (versus unipolar) disorder, but one study found that quality of life among people with bipolar disorder was significantly compromised compared to the general population, particularly with regard to
(a) physical and social functioning, (b) physical and emotional role limitations, (c) vitality, and (d) mental and general health (Arnold, Witzeman, Swank, McElroy, & Keck, 2000). An additional study showed that participants with bipolar disorder were significantly more impaired on these measures than those with other mood, anxiety, and substance use disorders (ten Have, Vollebergh, Bijl, & Nolen, 2002). A third study found that the depressive episodes and residual depressive symptoms characteristic of bipolar II were most strongly associated with poor emotional quality of life, even after controlling for potentially confounding variables, such as socioeconomic status and life stressors (Zhang et al., 2006).

**Family Considerations**

Marsh (1999) stated that because serious mental illness has a powerful impact on families as well as individuals, there is a sound rationale for including families in treatment approaches. Family members often assume the role of caregivers, as they might with any chronic health problem, and as informal case managers and advocates they can play an important role in the family member’s treatment, rehabilitation, and recovery. Marsh also reported that family attitudes and behaviors have been shown to affect the course of serious mental illness, including bipolar disorder. Thus, an educated and supportive family can be a significant asset for the patient and mental health professionals.

Mental illness in a family can be an enormous stressor, and the resulting trauma and exhaustion can leave other members at risk for stress-related physical and mental health problems (Lefley, 1996). Subjective burdens experienced by the family can include grief, loss of hopes and expectations for the future, chronic sadness, and the turmoil of the emotional roller coaster of acute episodic illness cycles (Marsh, 1999). Marsh stated that families also deal with objective burdens, such as symptom-related behavior, care-giving responsibility, family disruption, ongoing stress, problems with healthcare delivery systems and insurance, financial problems, and the social stigma associated with mental illness.

The dynamics of family systems can significantly affect how well families cope with a mentally ill member (Marsh, 1999). Family members are impacted to different degrees, and the impact may depend on their life phase and roles within the family system. Most of the research has focused on parents of people with mental illness, even though approximately 33% of patients go home to a spouse rather than a parent after hospitalization (Marsh). In addition to parents and spouses, siblings and children of the mentally ill client may be overwhelmed or unable to cope, experience alienation and guilt, or be forced to assume roles for which they are not developmentally ready. Family interventions for all members should be designed to target three essential family needs: "information about mental illness and its treatment, skills to cope
with the illness and its consequences, and support for themselves” (Marsh, p. 361). Understanding not only the idiosyncrasies but the family system of a client will provide insight into the most appropriate and effective evidence-based treatments.

EVIDENCE-BASED PSYCHOSOCIAL INTERVENTIONS

Miklowitz and Otto (2006) reported that environmental factors and life events play a powerful role in the frequency of bipolar disorder episodes and in recovery rates. For example, events that disrupt sleep/wake rhythms or goal-related achievements (e.g., high scores on the Graduate Record Examination) are correlated with the onset of manic episodes. Psychological factors such as cognitive-attributional styles and dysfunctional attitudes interact with life events to precipitate increases in manic and depressive symptoms. Where bipolar disorder is concerned, individuals have a predisposed sensitivity to elements of both nature and nurture.

Social and familial support systems also affect the course of bipolar disorder. For example, lack of a social support system predicts longer recovery time from a manic, depressed, or mixed episode, as well as higher levels of residual depression (Johnson, Winett, Meyer, Greenhouse, & Miller, 1999). Patients whose parents or spouses express high levels of criticism, hostility, or emotional overinvolvement during or immediately after an acute episode are more likely to relapse or have continued severe symptoms in the year following the episode (Miklowitz & Otto, 2006). Family-based treatments focus on establishing stable daily routines, consistent caretaking, and medication compliance (Morris, Miklowitz, & Waxmonsky, 2007). Taken together, these findings suggest specific components for therapeutic interventions.

Our review of the literature indicated that four therapeutic interventions are primarily used to treat bipolar disorder. Most have been used individually with patients as well as with families, and some have also been used in individual and family group settings (Morris et al., 2007). The four modalities have elements in common, such as the importance of medication adherence and psychoeducation. Psychoeducation is often used as a control condition for other interventions in research studies (Miklowitz & Otto, 2006; Miklowitz et al., 2007; Rizvi & Zaretsky, 2007). Each of the interventions is research-based, but the methodology and outcome variables of interest vary among the treatments studied. The importance of psychoeducation will be reviewed in addition to cognitive-behavioral therapy, family-focused therapy, and interpersonal and social rhythm therapy. Originally examined by Miklowitz and Otto within the context of the Systematic Treatment Enhancement Program, these authors present the modalities in a practical fashion in an attempt to reach counselors who can integrate them into their practice.
Psychoeducation

Psychoeducation provides information on mental health to patients, teaches symptom recognition, and facilitates development of individualized coping strategies for illness management (Zaretsky, Rizvi, & Parikh, 2007). Group is the most common format for these interventions, although they may be used individually and often include the family in a limited way (Rizvi & Zaretsky, 2007). Psychoeducation generally consists of at least three sessions teaching patients how to use self-management tools, such as self-care workbooks; educational videotapes addressing the diagnosis, course, treatment, and management of bipolar disorder; and drafting individualized relapse prevention plans (Miklowitz et al., 2007).

Psychoeducation has shown efficacy in improving patients’ attitudes toward and compliance with medication regimens (Miklowitz et al., 2007). For example, clients who received 21 sessions of psychoeducation over nine months showed a significant reduction in relapse rates and depressive symptoms and episodes, and the results held even when controlling for medication compliance. In addition, when individual was compared with family psychoeducation, family psychoeducation patients had fewer relapses and hospitalizations.

According to Miklowitz and Otto (2006), group psychoeducation may be a cost-effective alternative to individual or family therapy. In a group patients may feel less stigma, gain increased knowledge and acceptance of the disorder, and learn illness management strategies. A group of 29 bipolar clients demonstrated increased knowledge of the disorder and 70% identified and achieved a behavioral goal (e.g., finding employment) after completing a five-week manual-based psychoeducation group (Bauer, McBride, Chase, Sachs, & Shea, 1998).

Cognitive-Behavioral Therapy

The cognitive-behavioral therapy framework proposes a self-perpetuating cycle of reactions to cognitive and affective symptoms that impede functioning and exacerbate the psychosocial problems and stressors characteristic of bipolar disorder (Basco, Ladd, Myers, & Tyler, 2007). The goal of cognitive behavioral therapy is to target cognitive, behavioral, and affective changes in depression and mania and help the patient manage the disorder by stopping the progression of episodes. Clinicians challenge clients’ negative self-statements, encourage balanced interpretations of life events, and evaluate the nature of dysfunctional belief systems (Miklowitz et al., 2007).

The treatment goals of cognitive-behavioral therapy include educating clients about the disorder and how to manage it, and how environmental factors as well as client thoughts and behaviors affect its course (Basco et al., 2007). Several additional components help clients recognize and respond to symptoms that precipitate the onset of affective episodes (prodromal symptoms); improve and
maintain adherence to medication regimens; make lifestyle modifications, including stress reduction and sleep/wake cycle regulation; manage cognitive and behavioral symptoms; and resolve and prevent psychosocial problems, such as relationship, financial, or work-related issues.

**Family-Focused Therapy**

Family-focused treatment is an approach characterized by modules consisting of psychoeducation, communication skills training, and problem-solving skills for illness management (Morris, Miklowitz, & Waxmonsky, 2007). It may increase families' ability to provide structure, enhance adherence to treatment, and delay or reduce the number of relapses (Morris, Miklowitz, & Waxmonsky). Clinicians also address patient and family member affective reactions to the illness, prognosis, and treatment, and help them develop coping strategies for their specific family context so as to minimize the development of high-expressed-emotion attitudes that increase the risk of relapse (Miklowitz, 2007). Development of family-focused therapy was informed by consistent findings about expressed emotion and its role in the course of mood disorders (Morris et al., 2007).

According to Morris et al., (2007), treatment is flexible about which family members or other caregivers are involved, and it is provided to families individually, usually over a nine-month period. The six core elements of family-focused therapy are to (a) assist clients and families in integrating their experiences of the mood disorder; (b) accept the likelihood of future episodes; (c) accept the necessity of medication for symptom control; (d) distinguish between the client and the disorder; (e) recognize and cope with stressors that trigger recurrences; and (f) reestablish familial relationships after an acute episode (Morris et al.).

Culver, Arnow, and Ketter (2007) reviewed several studies and concluded that family-focused therapy may be a useful adjunct to medication for decreasing the risk of relapse and hospitalization characteristic of bipolar disorder. A random controlled trial compared nine months of home-based family-focused therapy with medication to pharmacotherapy and two sessions of crisis management (Miklowitz, 2007). Clients began treatment while still in the hospital or just after onset of an acute episode. At two-year follow-up, the family-focused therapy group had less severe symptomology and recurrence of depression, longer remission periods, and increased adherence to medication regimens (Miklowitz; Miklowitz & Otto, 2006; Morris et al., 2007; Zaretsky et al., 2007). High-expressed-emotion families benefited most from family-focused therapy (Miklowitz).

A UCLA study compared nine months of family-focused therapy and medication to individual psychotherapy and medication for participants with a history of hospitalizations for mania (Miklowitz, 2007). At one-year follow-up
the family-focused therapy group was significantly less likely to have relapsed or been rehospitalized, suggesting that patients were able to avoid rehospitalization because of family support, and they and their families were able to recognize early indications of relapse and seek medical intervention.

Miklowitz (2007) found that improvements in medication adherence and increased positive family communication explain most of the observed variation in less severe manic and depressive symptoms. Morris et al. (2007) suggested that family-focused therapy is an effective adjunct to pharmacotherapy, but that gains are most fully realized at the end of the treatment period and in the subsequent year, because clients and families need time to integrate and implement their new self-management, communication, and problem-solving skills. These studies also demonstrated the need for a large number of sessions, which must be considered in the context of healthcare resources and third-party-payer constraints (Zaretsky et al., 2007).

**Interpersonal and Social Rhythm Therapy**

Interpersonal and social rhythm therapy was developed by integrating standard elements of interpersonal therapy with social rhythm therapy, a treatment approach that attempts to stabilize social and circadian rhythms based on the hypothesis that “unstable or disrupted daily routines lead to circadian instability and affective episodes in vulnerable individuals” (Zaretsky et al., 2007). The hypothesis proposes that there are three interrelated “pathways” to episode recurrence; medication noncompliance, disruptions in social rhythms, and stressful life events (Hlastala, Frank, Mallinger, Thase, Ritenour, & Kupfer, 1997). Interpersonal and social rhythm therapy is a model-driven psychotherapy specifically for bipolar disorder that incorporates elements fundamental to psychoeducation and cognitive behavioral therapy (Zaretsky et al., 2007).

Interpersonal and social rhythm therapy emphasizes the need for regular sleep/wake cycles to keep moods stable, and clients are asked to keep detailed records of daily and nightly activities, levels of social stimulation, sleep, and mood (Miklowitz et al, 2007). The phases of interpersonal and social rhythm therapy include (a) identifying a key interpersonal problem area; (b) setting targets for regulating meals, exercise, and sleep; (c) making plans for keeping rhythm stable when disruptive social events occur; and (d) developing strategies to manage the priority interpersonal problem area (Frank, 2007).

Few research studies have been published evaluating interpersonal and social rhythm therapy; it did not appear in the literature until the late 1990s (Hlastala et al., 1997). In the first random controlled trial of interpersonal and social rhythm therapy (Frank et al., 2005), 175 bipolar patients were given either interpersonal and social rhythm therapy or intensive clinical management weekly during the acute phase of illness, biweekly after stabilization, and then monthly for a total treatment duration of two years (Frank, 2007). There were
no differences found between the treatment groups in terms of time to stabilization or remission rate over the two-year period, but the patients who received interpersonal and social rhythm therapy in the acute phase of illness experienced longer episode-free periods (compared to pre-intervention) in the maintenance phase, and the decreased likelihood of recurrence was correlated with increased stability in their social and sleep routines. Frank found that patients who received the same treatment modality for both phases of treatment, whether that treatment was interpersonal and social rhythm therapy or intensive care management, did better in terms of recurrences and symptom level. According to the central tenets of interpersonal and social rhythm therapy, this outcome may provide additional evidence of the sensitivity of bipolar patients to stability of social rhythms, including treatment factors (2007).

Miklowitz et al. (2007) randomly assigned 152 depressed outpatients to nine months of either interpersonal and social rhythm therapy, cognitive behavioral therapy, or family-focused therapy, or three sessions of psychoeducation. They then compared ratings from each group on quality of relationships, work or other role functioning, and recreational activities. Only the family-focused therapy group rated overall satisfaction more highly than the interpersonal and social rhythm therapy group, followed by the cognitive behavioral therapy and collaborative care groups. The authors concluded that all three intensive psychosocial interventions significantly improved subjects’ relationship and life satisfaction compared with collaborative care, but none had independent effects on work/role functioning or recreation satisfaction.

Integrated family and individual therapy is a treatment that combines individual interpersonal and social rhythm therapy with psychoeducational family focus therapy, alternating the two interventions weekly for up to one year (Morris et al., 2007). Compared to a group who received crisis management and medication, after controlling for the effects of medication integrated family and individual therapy clients had longer periods to relapse (compared to pre-intervention), and more improvement in depressive symptoms (Miklowitz et al., 2003). As with other treatment modalities, there were no significant differences in the stabilization of manic symptoms over the study period.

**IMPLICATIONS FOR COUNSELORS**

Therapeutic interventions for bipolar disorder are based on providing clients and their families with information about bipolar disease, treatments, and the importance of adherence to medication regimens. Therapeutic goals are to reduce client substance abuse, promote healthy diet and sleep habits, increase lifestyle regularity, identify and minimize interpersonal stressors, recognize early relapse symptoms, and seek prompt medical attention to prevent acute episodes.
Because the success of adjunct psychotherapies is highly client-specific, for maximum benefit treatments must be tailored to the needs of the individual client. For example, if the client has comorbid mental or substance abuse disorders, using both cognitive-behavioral and family-focused interventions may be more beneficial than any single approach (Rizvi & Zaretsky, 2007). Finally, the clinician might use manual-based interventions as a foundation on which to build an intervention specific to the client’s needs and, if appropriate, the needs of the family as a unit.

Counselor creativity in implementing evidenced-based interventions may be necessary for optimal results. The success of therapists in applying these interventions will depend on their ability to successfully integrate effective treatments, tailor them to the particular patient presentation and context, and develop new methods that allow patients’ individuality to determine which treatments should be explored (Rizvi & Zaretsky, 2007). Counselors might also consider whether they can help collect data in support of intensive psychosocial interventions.

CONCLUSION

Bipolar disorder is a devastating illness for patients and their families. Due to the complex and pervasive physiological, psychological, and social dimensions of the disorder, it remains a diagnostic and treatment challenge for the entire spectrum of professionals who work with this population. The chronic nature of bipolar disorder and the persistence of subdromal symptoms between acute illness episodes often results in significantly compromised psychosocial functioning in these clients throughout their lifespan.

Research clearly supports the use of psychoeducation, cognitive-behavioral therapy, family-focused therapy, and interpersonal and social rhythm therapy, in tandem with pharmacotherapy, to improve clinical and quality of life outcomes for people with bipolar disorder. In sum, evidence-based psychotherapeutic interventions in conjunction with medication management appear to increase therapeutic effectiveness; even brief psychoeducational interventions appear to be superior to collaborative care or crisis management alone. Because of the disruption and chaos that bipolar disorder can cause, families or other caregivers should be brought into the therapeutic process if possible. Individuals with bipolar disorder are at high risk of divorce, family problems, and social isolation, and interventions that create or strengthen family and other social bonds will be valuable. If individuals with bipolar disorder can obtain the medical and psychosocial interventions required to manage their illness, it is likely that the high social costs of this disorder can be reduced.
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Occupational therapy for people with psychotic conditions in community settings: a pilot randomized controlled trial

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Occupational therapy for people with psychotic conditions in community settings: a randomized controlled trial

Abstract

Objectives: To investigate the effectiveness of a long established intervention, occupational therapy for people with psychotic conditions, and to inform future research designs.

Design: A pilot randomized controlled trial.

Setting: Two community mental health teams in a UK city.

Participants: Forty-four adults with schizophrenia or other psychotic conditions, eligible for enhanced care and having functional problems.

Interventions: Twelve months of individualised occupational therapy (OT) in community settings, as an adjunct to usual care and compared to treatment as usual (TAU). A two to one randomisation ratio was used to enable more people to receive OT.

Outcome measures: Social Functioning Scale (SFS), Scale for the Assessment of Negative Symptoms (SANS) and employment.

Results: Both groups’ scores on SFS and SANS showed significant improvement over 12 months. For SFS, the OT group scores were: mean difference = 2.33, CI: 0.39 to 4.27, t = 1.525, P = 0.020 and the TAU group were: mean difference = 6.17, CI: 1.04 to 11.29, t = 2.65, P = 0.023. For SANS, OT group scores were: mean difference = -16.25, CI: -22.94 to -9.56, t = -4.99, P <0.001 and the TAU group: mean difference = -17.36, CI: -29.78 to -4.94, t = -3.12, P = 0.011. There were no differences between the two groups on any of the outcome measures. After 12 months the OT group showed clinically significant improvements that were not apparent in the control group. The OT group showed clinical improvement in 4 subscales of the SFS: relationships, independence performance, independence competence, and recreation. Out of 30 people receiving OT those with a clinical level of negative symptoms reduced from 18 (64%) to 13 (46%) P = 0.055.
Conclusion This pilot study suggested that individualised occupational therapy may contribute to recovery but more focus is recommended on people’s cognitive abilities and employment.
Introduction

Further research is needed on what is effective in the rehabilitation of people with psychotic conditions. This client group mostly comprises people diagnosed with schizophrenia, but also includes people with schizoaffective disorders and those affected by bipolar disorder with psychotic symptoms (1). The international lifetime prevalence for schizophrenia has a median of 4 per 1000 people (1.6 – 12.1) with higher rates in developed countries (2). People with psychotic conditions tend to experience difficulties in social functioning, self care and cognitive function (3), residual negative symptoms (4) and high rates of unemployment and social exclusion (5). Cognitive deficits and negative symptoms such as impoverishment of thought (alogia), inability to initiate or sustain purposeful activities (avolition) and lack of energy (anergia) continue over time and contribute to long term disability (4).

There is no conclusive evidence that any specific therapy intervention improves social functioning and negative symptoms for people with psychotic conditions. Programmes using behavioural therapy techniques to reward target behaviours with tokens may have beneficial effects on negative symptoms but have been limited to long stay ward environments and not rehabilitation in the community (6). Morita therapy, which employs a psychotherapy based on eastern philosophy and engages people in constructive behaviours, has shown some early positive impact on negative symptoms and social functioning but only in hospital settings and lacks systematic investigation (7). Music therapy has been shown to have some beneficial but inconsistent effects on negative symptoms and social functioning (8). There is more promising evidence that cognitive remediation therapy or integrated treatment strategies may improve social functioning and reduce negative symptoms. (3,9)

Regarding employment, the Individual Placement and Support model of supported employment has been found to be significantly more effective
than other strategies. However a systematic review of Individual Placement and Support found that only 34% of people with severe mental illness attained competitive employment at 12 months, suggesting that work remains a substantive challenge for many people (10).

The focus for this study was the effectiveness of the established practice of occupational therapy. Although evidence based practice generally validates novel treatments as more effective than older therapies (11), established therapies that are routinely delivered do merit investigation. Occupational therapy draws on the emerging discipline of occupational science, which asserts that engagement in meaningful and satisfying occupations contributes towards health and wellbeing, social inclusion, improved functioning and self respect. (12) Occupational therapy has contributed towards the treatment and rehabilitation of people with severe mental health problems since it emerged at the beginning of the 20th century in the USA (13) and became formally established with training standards in 1920. (14) There are currently approximately 11,000 occupational therapists practicing in primary and secondary mental health care in the UK, and this is replicated in several other countries (15).

There has been only suggestive evidence that mental health occupational therapy is effective for people with psychotic conditions. Three small single cohort studies reported that occupational therapy may be beneficial. (16-18) A UK study combining occupational therapy and care management for 37 people with psychosis in the sole care of their GP surgery showed improved scores on the Social Functioning Scale (SFS) with a mean difference of 6.9 (CI 4.2-9.5) p<0.001. (16) Another UK study of 12 sessions of life skills training for people with schizophrenia individualised to each client's goals and delivered by occupational therapists in the 13 participants' homes, showed a reduction in negative symptoms over time (p = 0.059) but a non-significant decrease in the group's mean SFS scores (109 to 104). (17) A study of occupational therapy plus supported employment for 52 people with schizophrenia in a Japanese psychiatric hospital showed improved social
functioning, reduced time in hospital and reduced risk of hospitalization.\textsuperscript{(18)} A Brazilian RCT investigating group and individual occupational therapy as an adjunct to Clozapine for 26 people with treatment-resistant schizophrenia found the experimental group significantly improved compared to usual care. However, the outcome measures for performance of activity, psychotic symptoms, social interaction and personal care relied on participant observation which may have introduced bias into the study. A further weakness of this study is that it did not have an active control group.\textsuperscript{(19)}

The effectiveness of occupational therapy as an established mental health intervention has not been conclusively or systematically evaluated using controlled studies in any country. The aim of this study was to investigate the feasibility of a RCT design to inform a future fully powered study within a European health and cultural context. A parallel qualitative study illuminated the findings.

Methods

Study Design

Our study was a pragmatic, prospective, randomised controlled trial of community based occupational therapy as an adjunct to usual care for people with psychotic conditions. The pragmatic trial investigated the effectiveness of the experimental intervention in normal practice settings. A heterogeneous sample in terms of diagnosis was chosen in order to replicate clinical practice and increase the external validity of the findings \textsuperscript{(20)}. Similarly, participants were identified according to the diagnosis on their medical records rather than through a structured clinical screening process.

Participants

From June to December 2004, following ethical approval from the local ethics committee, 44 people over the age of 16 years were recruited by their care coordinators from two NHS
community mental health teams in a northern UK city that served diverse communities in terms of deprivation and ethnicity. Participants gave written consent after having the study explained to them in detail by one of the researchers. People were included with psychosis for any duration, eligibility for an enhanced care programme\(^{(21)}\) and scoring 2 or more on at least one of the Health of the Nation Outcome Scales for problems with activities of daily living, disability or occupation and activities. People with dual diagnosis or physical/sensory disabilities were included but people with organic brain disorders were excluded.

**Randomisation**

Those consenting were randomised to allow a 1 in 3 chance of allocation to treatment as usual (TAU) and a 2 in 3 chance of allocation to occupational therapy plus usual care. This 2:1 ratio was selected at the request of the host teams who were concerned about restricting access for their clients to an established therapy. Randomisation used stratification by gender and treatment team, and random permuted blocks of sizes 3 and 6. A remote trials unit operated the computerised randomisation process and concealed the sequence and allocation from the research team by telephoning the treatment teams directly. The two assessors from the research team were blind to the allocation. The participants, therapists and care coordinators were aware of the allocation and were repeatedly reminded to keep the assessors blind. If blinding failed, the assessment was handed over to the other assessor who remained blind to allocation.

**Interventions**

*Occupational therapy*

The intervention schedule that defined occupational therapy was developed using consensus research methods with experienced practitioners, following a previous review of the literature and expert consultation.\(^{(22,23)}\) The schedule specified an individualised and
client centred approach and comprised 82 components within the 11 stages of the occupational therapy process. The schedule can be accessed at: 
http://www.shu.ac.uk/research/hsc/downloads/Final%20Int%20Sched%20sequenced%20black%20and%20white.doc. The functions of the therapist were specified\(^{(24)}\) such as to ‘select and adapt activities to meet the individual goals of the client’, but not the forms of therapy such as number of sessions, type of activity or venue, or the mix of individual and group sessions. The majority of components were specific to occupational therapy but a minority of generic components was included as these were required by all members of the multi-disciplinary team (e.g. risk management). The intervention schedule is summarized below:

The occupational therapist, involving family, other informal carers or staff as required:

- Engages with the client, establishing the client’s preferences on how to work together and the client’s history, interests and concerns regarding occupation.
- Assesses the client’s competency in performing the client’s routines, roles and occupations in daily life, including self care, productivity and leisure.
- Identifies the client’s strengths and the barriers that impact on occupational performance, including the client’s social and physical environments.
- Collaboratively sets and prioritizes goals concerning occupation and plans an individually tailored programme of therapeutic activities. These are selected and adapted using detailed activity and environmental analysis, grading and sequencing.
- Engages the client in planned activities, teaching specific skills and encouraging the client to initiate actions, use support, participate in group work, work alongside the therapist, or develop routines and balance of activities as planned.
• Reviews with the client the meaning and impact of the client’s chosen activities, encouraging the client to develop strategies that use occupations to improve wellbeing and alleviate psychotic symptoms.

• Collaboratively continues assessing, reviewing outcomes, updating goals and modifying actions in order that the client achieves her or his desired occupations.

The intervention was delivered by three senior occupational therapists for up to 12 months for each participant. Within this period the number of sessions was not specified as this was tailored to each individual. Training was not given as the intervention was established occupational therapy practice. Performance was monitored through structured clinical supervision and adherence to the intervention schedule was audited using the participants’ therapy notes.

_Treatment as usual_

This was provided by non-occupational therapist multi-disciplinary members of community mental health teams that specialised in the continuing care of people with psychotic conditions. Clients received medication, reviews by their psychiatrist and the enhanced level of care management specified by the UK Care Programming Approach.\(^{(25)}\) The care coordinators provided a range of interventions and support from within the team and through referrals to other services. Team members had received training in psychosocial interventions that included relapse prevention strategies and family interventions and some were trained in psychological therapies.\(^{(26)}\) These were delivered according to the needs of individual clients and the time that staff could offer, allowing for the demands of their caseloads.
Assessment

The interventions were delivered between June 2004 and Dec 2005. Assessment was performed at baseline, 6, 9 and 12 months, and data was collected in face to face interviews. No post-intervention follow-up was carried out. The first assessment was carried out at 6 months as advised by clinicians who reported that with this population improvement is not expected for some months. A limited number of outcome measures were chosen in order to maintain engagement with people who have limited concentration and high levels of distress. The primary measure was the Social Functioning Scale (SFS) which was developed and validated for people with schizophrenia.\(^{(27)}\) Seven subscales measure withdrawal, relationships, social activities, recreation, independence competence, independence performance and employment. Raw scores are transformed to give each subscale equal weighting. The overall mean score ranges from 52 to 139, and the average point for this client group is 100. The secondary outcomes were negative symptoms of schizophrenia, measured with the Scale for the Assessment of Negative Symptoms (SANS)\(^{(28)}\), and engagement in employment related activity within the last 3 months. Adverse events were recorded including suicide and psychotic relapse that required hospitalisation.

Inter-rater reliability

This was conducted for the SFS. We recruited 10 volunteers who attended local mental health day centres who were not participants of the trial. Both assessors interviewed each person individually using the SFS questionnaire and recorded the interviews on video. The assessors then rated each other’s videos, to generate 20 pairs of assessment data using the SFS transformed total mean scores. A Bland-Altman chart was used to measure agreement between two sets of continuous data\(^{(29)}\).
Statistical methods

Data analyses were based on an intention to treat principle unless stated otherwise. Missing values for any individual questions within the outcome measures were imputed using interpolation, when values were available either side of a missing time point the mean of the two values were imputed, otherwise the last observed value was carried forward. Baseline characteristics were summarised as number of subjects (%) for categorical data and mean (standard deviation) for continuous data. The outcome data was similarly summarised for the base line, six, nine and twelve months time points. T tests were carried out to compare scores over time and between groups and changes in clinical improvement were investigated using Fisher's exact test. Additional analyses included cross tabulation to investigate clinical significance and adjusting for base line differences using analysis of covariance (ANCOVA).

Results

Flow of participants through the trial

Six of the 50 people referred to the trial declined to take part. One person was about to move out of the area and the others did not disclose their reasons. Forty two out of 44 participants completed the trial. One person in each group received the intervention intended for the other group, through team members making referrals to other services. By the end of the trial the allocation for five people had become known to both assessors. See Fig 1.

Inter-rater reliability of the Social Functioning Scale

Overall mean scores showed a mean of 98.76 (range: 88.32 to 119.57) and standard deviation of 8.07. The results from measuring agreement between two sets of continuous data showed a mean difference and bias of -0.029, with a standard deviation of 0.761. The
limits of agreement were therefore -1.54 to 1.49. Relative to the range this is small and considered acceptable.

**Base line characteristics**

The age range was 18 – 60 years for the OT group and 21 – 56 years for the TAU group. The duration of psychotic condition ranged from 1 – 29 years for the OT group and 4 – 36 years for the TAU group. There were noticeable differences between groups in diagnosis and marital status due to chance in this small study, but these were not statistically significant. The OT group had a higher proportion of people diagnosed with ‘other psychotic disorders’ that included people who have not yet been given a definitive diagnosis, and a higher proportion of people who were married or living with a partner. The TAU group had a higher proportion of people with bipolar disorder. See Table 1.

**Length of occupational therapy intervention**

Of the 30 people in the OT group 83% received at least 11 months of the 12 months intervention. Eighteen received 12 months and 7 received 11 months. One participant decided to terminate therapy at 10 months, one went on a long holiday at nine months, two participants were discharged having achieved their goals at 8 months and 4 months. One person moved out of the area after one month. One person received no occupational therapy as shown in figure 1.

**Outcomes**

The mean scores for social functioning and negative symptoms, at each time point are shown for each group in Table 2.

**Social functioning**

Compared to base line, the OT group showed significant change at 12 months in the SFS overall mean scores (Mean difference = 2.33, CI: 0.39 to 4.27, t = 1.525, P = 0.020).
Compared to baseline, the TAU group approached significant change at 6 months (Mean difference = 3.68, CI: -0.02 to 7.38, $t = 2.19$, $P = 0.051$); and achieved significant change at 9 months (Mean difference = 5.04, CI: 1.37 to 8.72, $t = 3.00$, $P = 0.012$); and at 12 months (Mean difference = 6.17, CI: 1.04 to 11.29, $t = 2.65$, $P = 0.023$). There was no significant difference between the two groups’ change scores when compared at 6, 9 or 12 months.

**Negative symptoms**

The OT group showed significant improvement over time in the total SANS scores at 6, 9 and 12 months. The results were: at 6 months compared with baseline: Mean difference = -9.615, CI: -16.04 to -3.19, $t = -3.08$, $P = 0.005$; at 9 months compared with baseline: Mean difference = -11.885, CI = -18.31 to -5.46, $t = -3.81$, $P = 0.001$; and at 12 months compared with baseline: Mean difference = -16.25, CI: -22.94 to -9.56, $t = -4.99$, $P < 0.001$. The TAU group showed significant improvement in the total SANS scores at 6 and 12 months only. The results were: at 6 months compared with baseline: Mean difference = -11.18, CI: -22.27 to -0.09, $t = -2.25$, $P = 0.048$; and at 12 months compared with baseline: Mean difference = -17.36, CI: -29.78 to -4.94, $t = -3.12$, $P = 0.011$. There was no significant difference between groups on their change scores over time at 6, 9 or 12 months.

**Outcomes adjusted for base line differences**

As at baseline there were noticeable differences between the two groups on diagnostic categories, marital status, the SFS scores and SANS scores, the groups were compared using ANCOVA with change in SFS or SANS score over time used as the dependent variable. Table 3 shows that there was no significant difference between the groups even when adjusted on either SFS or SANS outcomes.
Clinically significant change

The OT group’s social functioning subscales showed clinically significant improvement for certain subscales: relationships, independence performance and independence competence and the clinical improvement for recreation approached statistical significance (Table 4). Clinically significant change was defined as attaining a score of 116 or more, indicating that the person was no longer a cause for concern and did not require interventions. The TAU group’s subscales showed that clinical change was not statistically significant. Table 4 shows that very few people attained clinically significant improvement on their overall mean score. There were no statistically significant differences between the two groups at any time point.

A cross tabulation of the OT group’s SANS scores showed clinical improvement from baseline to 12 months that approached statistical significance (Table 3). The cross tabulation of the TAU group’s SANS scores showed no clinically significant change using Fisher’s Exact Test (P = 0.545). Clinically significant change was defined as attaining less than 3 in any subscale’s global score as the SANS scales state that scores of 3 or more indicate a clinical problem.

There were no adverse events reported.

Qualitative findings

The parallel qualitative study which included 9 of the 12 people in the TAU group, showed that 4 of these participants received components of the occupational therapy intervention as described in the intervention schedule. This included tailoring support to the individual priorities and preferences of the client when choosing activities. These interventions were delivered by social workers, nurses or support workers. The qualitative study will be reported fully elsewhere.
Employment

In the OT group (n = 30), 3 participants were employed at baseline assessment, and a further 2 became employed during the intervention period. The control group (n = 12) had no-one employed at baseline and the person who inadvertently received occupational therapy became employed. The numbers were too small to compare groups.

Discussion

Statement of principle findings

Both groups improved significantly over time for social functioning and negative symptoms but there were no differences between the two groups on overall scores. The occupational therapy group showed clinically significant improvement in SFS subscales particularly for relationships, independence and recreation, and the clinically significant improvement in negative symptoms approached statistical significance. The TAU group did not show clinically significant changes. The small number of people engaging in employment related activity was disappointing.

Strengths and weaknesses of the study

The percentage of eligible participants who consented and completed the trial was extremely high (84%). We believe this to be a direct result of the significant involvement of service users in the design and the implementation of the study. The study also recruited a high percentage of participants from minority ethnic groups (23%) compared to the local population of 10.9%. This reflects the demography of this client group.

It was feasible to deliver occupational therapy that adhered to the intervention schedule but not feasible in the host setting to stop this intervention at 12 months as was intended in the protocol. This was due to concerns about continuity of care for vulnerable clients and
procedures are needed to manage this. One area for improvement in the design of this study was the use of care co-coordinators to identify eligible patients rather than sampling the whole case list. Some practitioners did not refer any of their patients. It may have been that only the most confident practitioners were prepared to engage in a study that was investigating their performance. This could have led to biased results and contributed to the positive results shown by the control group. Another improvement would have been to include an individualised outcome measure to complement the standardised measures, as discussed later.

The present study’s findings re-iterate the reports of the few other relevant studies, that there is only suggestive evidence that mental health occupational therapy is effective for people with psychotic conditions. Three single cohort studies suggested that occupational therapy may be beneficial.\(^{(16)}\)\(^{(17)}\)\(^{(18)}\)\(^{(19)}\)

A drawback of the present study may have been that it did not target people’s cognitive function, unlike an Israeli study of 58 people with schizophrenia that compared 12 months dynamic cognitive intervention applied to daily living situations and group therapy, to traditional occupational therapy, all delivered by occupational therapists.\(^{(32)}\) The dynamic cognitive group showed improved scores for memory and thought processes, a higher percentage obtained work in the open market, but there were no difference for instrumental activities of daily living. The study was limited to a particular local population with unspecified ethnicity, so generalisability is restricted. In a UK RCT of cognitive rehabilitation compared to occupational therapy, both groups improved over time, but there were no between group differences post intervention, except for improved self-esteem in the cognitive rehabilitation group.\(^{(33)}\)
Similarly, between group differences were not shown post intervention in an American RCT of skills training compared to occupational therapy except in measures of self-esteem.\(^{(34)}\) Interestingly this study found that skills training showed significantly greater improvement on a measure of independent living skills at 2 year follow-up, after the community case managers had been instructed to encourage their clients to generalise the skills learned in the training sessions to every day situations. This suggests that rehabilitation interventions should be researched as an element of inter-professional practice with the contributions of all team members included in the research design.

**Implications of the study**

It could be argued that the study participants reached a limit in their potential to improve due to their long term disabling conditions. However, we suspect that limited improvement in the SFS overall score was due to a lack of sensitivity in the scores due to ceiling effects.\(^{(35)}\) The OT and TAU groups reached 104 and 105 respectively post treatment. Similar studies reported scores of 108 following an integrated care programme,\(^{(36)}\) 105 following occupational therapy and care management\(^{(16)}\) and 104 following life skills training.\(^{(17)}\) All these are below the clinically significant score of 116 at which no further intervention is required. Alternative instruments to measure function are recommended.

It was promising that occupational therapy was associated with some positive results concerning clinically significant improvement, beyond the average scores for this client group. Improvement in the social functioning subscales may have been due to the individually tailored occupational therapy programmes that were designed around each person’s unique aspirations for their daily lives. Such individualised programmes may contribute towards meaningful recovery but are not designed to improve a person’s overall functioning.
Unanswered questions and future research

A study objective was to estimate parameters for future trials and these results will be used to inform the power calculation for a larger study. However, standardised measures may not be sensitive to improvement in a discreet area of living that has been targeted by an individually tailored programme. For instance, one of the study participants focused only on passing a GCSE at college and his achievement was not reflected in his outcome scores. It may be advisable in similar studies to add an individualised measure such as Goal Attainment Scaling, the Canadian Occupational Performance Measure or Seiqol.\(^{37,38}\)

The major challenge to the feasibility of the study was the contamination between the two groups, with evidence from the parallel qualitative study that some treatment as usual participants received occupational therapy. Contamination could have been due to interdisciplinary working over a long period of time, with occupational therapy being an established rather than a new intervention. Team members usually discussed cases together and practiced joint working with the occupational therapists. They shared strategies and information on accessing community resources and facilitating clients to engage in activities of their choice. This could contribute to occupational therapy not being separate or additional to the routine practice of social workers and nurses. Lack of difference between the two groups’ outcomes may also have been due to:

- a) chance: the study was not powered to detect significant differences between groups
- b) variation in the therapists’ and care coordinators’ qualities rather than particular psychosocial interventions\(^{39}\)
- c) the positive impact of medication and psychosocial interventions on both groups
- d) a positive Hawthorn effect on staff when providing the control intervention, in response to their practice being scrutinised
e) the attention that was paid to the control group during repeat interviews and from the efforts of the research team to validate and retain their participation, including newsletters, greetings cards, payments of £10 shopping vouchers for each interview.

This study demonstrates the preliminary steps for the design and evaluation of complex interventions leading to recommendations for the development of improved trials in the future.\(^\text{(40)}\)

To conclude, this pilot study suggested that individualised occupational therapy may contribute to recovery but more focus is recommended on people’s cognitive abilities and employment. Although the results of this small study were not intended to be generalisable, the findings merit further studies. It is worth carrying out a future fully powered study of mental health occupational therapy, not as an isolated intervention, but within inter-professional practice. Suitable designs include a multi-centre cluster randomised trial with the team as the unit for randomisation or observational studies to provide supportive data.\(^\text{(41)}\) To do this, outcome measures are required that are sensitive to the changes associated with individualised programmes of therapy and therapists’ qualities need to be factored in.

**Clinical Message**

- Limited evidence found individualised occupational therapy was associated with clinical improvement in social functioning and negative symptoms for people with psychotic conditions.
• Future research designs should investigate occupational therapy within inter-professional practice in mental health settings.

• Individualised outcome measures are required to investigate client-centred programmes of therapy.

Acknowledgements

We thank all the participants, the service user steering group, occupational therapists and community mental health teams, Sheffield Care Trust for their contributions.

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Statistical advice and support: Mike Campbell, Stella-May Gwini, Tracey Young.

Trial administrator: Melanie Hart.

Competing interests

None declared

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(4) Andreasen NC, Olsen S. Negative v positive schizophrenia. Definition and validation. Arch Gen Psychiatry 1982;39(7):789-94.


(22) Creek J. Occupational Therapy defined as a complex intervention. London: College of Occupational Therapists; 2003.


Table 1. Baseline characteristics of people with psychotic conditions who were randomised to occupational therapy or treatment as usual

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>OT n = 30</th>
<th>TAU n = 14</th>
<th>Total n = 44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD)</td>
<td>38.63 (10.9)</td>
<td>39 (8.6)</td>
<td>39</td>
</tr>
<tr>
<td>Duration of psychotic condition in years (SD)</td>
<td>12.27 (7.82)</td>
<td>13.79 (9.15)</td>
<td>13</td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10 (33.33)</td>
<td>5 (35.71)</td>
<td>15</td>
</tr>
<tr>
<td>Male</td>
<td>20 (66.67)</td>
<td>9 (64.29)</td>
<td>29</td>
</tr>
<tr>
<td>Ethnicity (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>23 (76.67)</td>
<td>11 (78.57)</td>
<td>34</td>
</tr>
<tr>
<td>Other</td>
<td>7 (23.33)</td>
<td>3 (21.43)</td>
<td>10</td>
</tr>
<tr>
<td>Diagnosis (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>20 (66.67)</td>
<td>8 (57.14)</td>
<td>28</td>
</tr>
<tr>
<td>Bipolar*</td>
<td>3 (10.00)</td>
<td>5 (35.71)</td>
<td>8</td>
</tr>
<tr>
<td>Other psychotic disorder*</td>
<td>7 (23.33)</td>
<td>1 (7.14)</td>
<td>8</td>
</tr>
<tr>
<td>Employed (%)</td>
<td>2 (6.67)</td>
<td>1 (7.14)</td>
<td>3</td>
</tr>
<tr>
<td>Education level (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not completed compulsory</td>
<td>1 (3.33)</td>
<td>0 (0.00)</td>
<td>1</td>
</tr>
<tr>
<td>School up to age 16</td>
<td>6 (20.00)</td>
<td>6 (42.86)</td>
<td>12</td>
</tr>
<tr>
<td>Further education 16 +</td>
<td>21 (70.00)</td>
<td>7 (50.00)</td>
<td>28</td>
</tr>
<tr>
<td>Degree level</td>
<td>2 (6.67)</td>
<td>1 (7.14)</td>
<td>3</td>
</tr>
<tr>
<td>Accommodation (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own/rented</td>
<td>24 (80.00)</td>
<td>12 (85.71)</td>
<td>36</td>
</tr>
<tr>
<td>Own/rented with support</td>
<td>1 (3.33)</td>
<td>1 (7.14)</td>
<td>2</td>
</tr>
<tr>
<td>Residential/nursing home</td>
<td>3 (10.00)</td>
<td>1 (7.14)</td>
<td>4</td>
</tr>
<tr>
<td>Homeless</td>
<td>2 (6.67)</td>
<td>0 (0.00)</td>
<td>2</td>
</tr>
<tr>
<td>Living alone (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives alone</td>
<td>16 (53.33)</td>
<td>8 (57.14)</td>
<td>24</td>
</tr>
<tr>
<td>Lives with other people</td>
<td>14 (46.67)</td>
<td>6 (42.86)</td>
<td>20</td>
</tr>
<tr>
<td>Marital status (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/living with partner*</td>
<td>7 (23.33)</td>
<td>1 (7.14)</td>
<td>8</td>
</tr>
<tr>
<td>Separated/divorced*</td>
<td>3 (10.00)</td>
<td>5 (35.71)</td>
<td>8</td>
</tr>
<tr>
<td>Single*</td>
<td>19 (63.33)</td>
<td>8 (57.14)</td>
<td>27</td>
</tr>
<tr>
<td>Other</td>
<td>1 (3.33)</td>
<td>0 (0.00)</td>
<td>1</td>
</tr>
</tbody>
</table>

* Noticeable differences between groups (differences are not statistically significant)

OT: occupational therapy, TAU: treatment as usual, SD: standard deviation
### Table 2: Outcome scores over time for the occupational therapy and treatment as usual groups

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>6 months</th>
<th>9 months</th>
<th>12 months</th>
<th>Change score, baseline to 12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Occupational therapy</td>
<td>Treatment As Usual</td>
<td>Occupational therapy</td>
<td>Treatment As Usual</td>
<td>Occupational therapy</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>N = 30</td>
<td>N = 14</td>
<td>N = 29</td>
<td>N = 12</td>
<td>N = 30</td>
</tr>
<tr>
<td><strong>SFS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SFS overall mean</td>
<td>101.7 (7.3)</td>
<td>100.3 (8.6)</td>
<td>102.3 (7.9)</td>
<td>102.9 (7.5)</td>
<td>104 (8.5)</td>
</tr>
<tr>
<td>Social Withdrawal</td>
<td>99 (9.8)</td>
<td>97.3 (9.5)</td>
<td>99.9 (12.3)</td>
<td>99.6 (8.70</td>
<td>103 (10.1)</td>
</tr>
<tr>
<td>Relationships</td>
<td>108.9 (19.1)</td>
<td>102.7 (13.1)</td>
<td>113.7(20.7)</td>
<td>108.4 (8.3)</td>
<td>111.8 (18.9)</td>
</tr>
<tr>
<td>Social Activities</td>
<td>108.4 (10.9)</td>
<td>105.5 (6.5)</td>
<td>104.3 (9.5)</td>
<td>105.9 (12.8)</td>
<td>107 (10.4)</td>
</tr>
<tr>
<td>Recreational Activities</td>
<td>98.2 (11.9)</td>
<td>99 (17)</td>
<td>96.8 (16.4)</td>
<td>98 (12.3)</td>
<td>102.3 (16.6)</td>
</tr>
<tr>
<td>Independence Competence</td>
<td>102.5 (12.2)</td>
<td>101.6 (18.8)</td>
<td>106 (15.3)</td>
<td>108.9 (15.2)</td>
<td>105.1 (13.1)</td>
</tr>
<tr>
<td>Independence Performance</td>
<td>101 (9.8)</td>
<td>97.9 (14.5)</td>
<td>101.5 (11.8)</td>
<td>104 (16.8)</td>
<td>102.9 (10.4)</td>
</tr>
<tr>
<td>Employment</td>
<td>93.9 (7.6)</td>
<td>98.3 (7.70</td>
<td>94.2 (9.2)</td>
<td>95.3 (7.4)</td>
<td>96.2 (9.7)</td>
</tr>
<tr>
<td><strong>SANS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>39.5 (23.1)</td>
<td>30.1 (21.6)</td>
<td>27.3 (16.5)</td>
<td>20.3 (10.1)</td>
<td>22.9 (19.2)</td>
</tr>
<tr>
<td>Blunting</td>
<td>10.2 (8.8)</td>
<td>5.8 (8.7)</td>
<td>6.9 (6.9)</td>
<td>2.4 (3.5)</td>
<td>5.8 (7.1)</td>
</tr>
<tr>
<td>Alogia</td>
<td>5.5 (5.3)</td>
<td>2.7 (5.4)</td>
<td>2.7 (2.5)</td>
<td>1.1 (2.6)</td>
<td>2.7 (3.3)</td>
</tr>
<tr>
<td>Apathy</td>
<td>9.7 (5.1)</td>
<td>8.1 (6.1)</td>
<td>7.6 (4.3)</td>
<td>7.8 (4.2)</td>
<td>5.7 (4.9)</td>
</tr>
<tr>
<td>Asociality</td>
<td>9.8 (5.4)</td>
<td>9.2 (4.9)</td>
<td>6.4 (5.2)</td>
<td>6.3 (3.4)</td>
<td>5.8 (5.4)</td>
</tr>
<tr>
<td>Attention</td>
<td>4.3 (3.7)</td>
<td>4.4 (3.5)</td>
<td>3.7 (3.8)</td>
<td>2.8 (2.6)</td>
<td>3.0 (3.5)</td>
</tr>
</tbody>
</table>

For the SFS higher scores indicate improvement. For SANS lower scores indicate improvement.

SD: standard deviation, SFS: Social Functioning Scale, SANS: Scale for the Assessment of Negative Symptoms
Table 3: Difference in outcome scores between intervention groups: Unadjusted and adjusted for key base line factors using ANCOVA

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Coefficient of the regression (difference)</th>
<th>95% CI</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SFS overall mean</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unadjusted difference</td>
<td>42</td>
<td>-0.987</td>
<td>-6.551 to 4.576</td>
<td>0.722</td>
</tr>
<tr>
<td>Difference adjusted for baseline SFS overall mean score</td>
<td>42</td>
<td>-3.124</td>
<td>-6.478 to 0.230</td>
<td>0.067</td>
</tr>
<tr>
<td>Difference adjusted for diagnostic groups&lt;sup&gt;b&lt;/sup&gt;</td>
<td>42</td>
<td>-2.879</td>
<td>-6.462 to 0.703</td>
<td>0.112</td>
</tr>
<tr>
<td>Difference adjusted for marital status&lt;sup&gt;b&lt;/sup&gt;</td>
<td>42</td>
<td>-2.804</td>
<td>-6.169 to 0.561</td>
<td>0.100</td>
</tr>
<tr>
<td><strong>SANS total score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unadjusted difference</td>
<td>39</td>
<td>9.410</td>
<td>-2.54 to 21.363</td>
<td>0.119</td>
</tr>
<tr>
<td>Difference adjusted for baseline SANS Total score</td>
<td>39</td>
<td>5.799</td>
<td>-2.972 to 14.569</td>
<td>0.188</td>
</tr>
<tr>
<td>Difference adjusted for diagnostic groups&lt;sup&gt;b&lt;/sup&gt;</td>
<td>39</td>
<td>6.117</td>
<td>-3.365 to 15.598</td>
<td>0.199</td>
</tr>
<tr>
<td>Difference adjusted for marital status&lt;sup&gt;b&lt;/sup&gt;</td>
<td>39</td>
<td>6.520</td>
<td>-2.411 to 15.452</td>
<td>0.147</td>
</tr>
</tbody>
</table>

a For SFS higher scores indicate higher function and for SANS higher scores indicate more severe problems.

<sup>b</sup> Also adjusted for the baseline outcome score.

SFS: Social Functioning Scale, SANS: Scale for the Assessment of Negative Symptoms.
Table 4: Clinically significant change in the two intervention groups over 12 months for social functioning and negative symptoms

<table>
<thead>
<tr>
<th></th>
<th>Occupational therapy</th>
<th>Treatment as usual</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of participants scoring ≥ 116 (%)</td>
<td>P value¹</td>
</tr>
<tr>
<td></td>
<td>Base line 12 months</td>
<td>Base line 12 months</td>
</tr>
<tr>
<td>Overall mean</td>
<td>2 (6.7) 2 (6.7)</td>
<td>N/A²</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>3 (10.0) 6 (20.0)</td>
<td>0.501</td>
</tr>
<tr>
<td>Relationships</td>
<td>8 (26.7) 11 (36.7)</td>
<td>0.028</td>
</tr>
<tr>
<td>Social activities</td>
<td>5 (16.7) 5 (16.7)</td>
<td>No change</td>
</tr>
<tr>
<td>Recreation</td>
<td>2 (6.7) 8 (26.7)</td>
<td>0.064</td>
</tr>
<tr>
<td>Independence performance</td>
<td>2 (6.7) 3 (10.0)</td>
<td>0.007</td>
</tr>
<tr>
<td>Independence Competence</td>
<td>5 (16.7) 7 (23.3)</td>
<td>0.006</td>
</tr>
<tr>
<td>Employment</td>
<td>1 (3.3) 3 (10.0)</td>
<td>0.100</td>
</tr>
<tr>
<td>SANS</td>
<td>Number of participants with any global score &lt; 3 (%)</td>
<td>P value¹</td>
</tr>
<tr>
<td></td>
<td>Base line 12 months</td>
<td>Base line 12 months</td>
</tr>
<tr>
<td></td>
<td>10 (35.7%) 15 (53.6%)</td>
<td>0.055</td>
</tr>
</tbody>
</table>

1:Fisher’s Exact; 2: No statistics computed because of a constant variable in the 2 way cross tabulation
SFS: Social Functioning Scale; SANS: Scale for the Assessment of Negative Symptoms
Fig 1: Flow of participants through the trial

OT: occupational therapy, TAU: treatment as usual
Bipolar Disorder

Bipolar Clinic Staff
bipolar disorder

Bipolar Clinic Staff

A Pan American Health Organization / World Health Organization Collaborating Centre
INTRODUCTION

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INTRODUCTION

This guide is for people with bipolar disorder, their families and anyone who wants to understand the basics of this illness, its treatment and management. It should not replace treatment from a physician or mental health professional. It can be used, though, as a basis for asking about and discussing bipolar disorder. This handbook covers many aspects of bipolar disorder and common questions. With respect to drug treatments, new medications are often being developed, and some may not yet have been available when this guide was published.

AUTHORSHIP

Bipolar disorder is an often-complex disorder that requires many different types of knowledge and expertise to treat. Effective treatment is usually collaborative and multidisciplinary; so too was the writing of this guide. We have deliberately stated authorship as the “Bipolar Clinic Staff” to reflect our commitment to collaboration. For the record, the contributors to the guide include Sagar Parikh, MD, FRCPC; Carol Parker, MSW, CSW; Robert Cooke, MD, FRCPC; Stephanie Krüger, MD; Roger McIntyre, MD, FRCPC; Alice Kusznir, OT, M.Ed.; and Christina Bartha, MSW, CSW. Additional input was provided by Lynnette Ashton, Mary Damianakis, Deborah Mancini and Lisa Zetes-Zanatta.

ACKNOWLEDGMENT

The authors would like to pay special tribute to our patients and their families who, through their openness, have taught us so much. We would also like to express our sincere appreciation to the patients and family members who gave so generously of their time in reviewing the manuscript and for their thoughtful comments and suggestions.

We also wish to thank the Mood Disorders Association of Ontario and Toronto for their assistance in the compilation of the list of Provincial Mood Disorder Associations.
1 What Is Bipolar Disorder?

Why Is Bipolar Disorder Called an “Illness”?

Everyone has ups and downs in mood. Feeling happy, sad and angry is normal. Bipolar disorder, or manic-depressive illness, is a medical condition in which people have extreme mood swings. Their moods may have nothing to do with things going on in their lives. These swings do not only affect mood, they also affect how people think, behave and function.

Bipolar disorder is no one’s fault. It does not come from a “weak” or unstable personality. It is a medical disorder that can be treated.

How Common Is Bipolar Disorder?

You or someone you care about may have been diagnosed with bipolar disorder. You may now feel alone in facing the problems of the illness, but you are not alone. About one to two per cent of adults worldwide suffer from bipolar disorder. Men and women are affected equally.

When Does Bipolar Disorder Begin?

More and more, the first signs of bipolar disorder are being recognized in adolescence or early adulthood. Yet the younger the person is when the symptoms first develop, the less typical the symptoms may be. The symptoms may then be mistaken for teenage distress or rebellion, so bipolar disorder is often not diagnosed until adulthood.

In some women, bipolar disorder may appear during pregnancy or shortly after it. Mania, or a “high,” after pregnancy occurs only in about 0.1 per cent of all cases. Depression is more common (see pp. 5–9 for symptoms of mania and depression). If you or someone you care about has developed depressive symptoms after pregnancy, and these symptoms are severe or last more than two weeks, you or she should seek help.

2 The Clinical Features of Bipolar Disorder

The Episodes of Bipolar Disorder

Bipolar disorder is an episodic (that is, recurrent) disorder. It typically consists of three states:

1. a high state, called “mania”
2. a low state, called “depression”
3. a well state, during which many people feel normal and function well.

The manias and depressions may be either “pure” episodes (they have only typical manic or depressive symptoms) or they may be “mixed” episodes (they may consist of a mixture of manic and depressive symptoms at the same time). Traditionally, mixed episodes have been associated with the manic phase of the illness, so terms such as “mixed mania” or “dysphoric mania” are often used to describe mixed states.

Types of Bipolar Disorder

Some people experience manic or mixed, depressed and well phases during their illness. Such people are said to have “Bipolar-I” disorder. A milder form of mania is called “hypomania.” People who have hypomania, depression and intervals without symptoms, but no full manic phases, are said to have “Bipolar-II” disorder.

Order and Frequency of the Various States

The manic/hypomanic, mixed and depressive states usually do not occur in a certain order, and their frequency cannot be predicted. For many people there are years between each episode, whereas others suffer more frequent episodes. Over a
Mania

Sometimes, a person may seem abnormally and continuously high, irritable or expansive for at least one week. If this change in mood is accompanied by other symptoms (see below) the person may be in a manic phase of the bipolar illness. Not everybody who enters a manic phase feels happy or euphoric. Instead, a person may feel very irritable, or may be terribly angry, disruptive and aggressive.

People in a manic phase do not just have mood symptoms. They must have at least three of the following symptoms to an important degree:

**Exaggerated Self-Esteem or Feeling of Grandeur**
People feel invincible or all powerful; they believe they understand “how the world works” or how to save it. They may feel they have a special mission in life (that is, God has sent them or given them special powers).

**Less Need for Sleep**
People feel rested after just a few hours of sleep. Sometimes they may not sleep at all for a few days or even weeks.

**Increased Talking**
People may talk very quickly, too loudly and much more than usual. They may like to tell jokes or rhyme words and may become angry when interrupted. They may keep switching topics and cannot converse properly with others.

**Flight of Ideas or Racing Thoughts**
People easily lose their train of thought, and have trouble interacting because they are easily distracted. They may be impatient with others who cannot follow their fast thinking and changing plans and ideas.
**Depression**

Depression can take many forms, and it often comes out of nowhere. The symptoms must last for at least two weeks, and must be present most days and last most of the day. Symptoms of depression in bipolar disorder include at least five of the following:

**Depressed Mood**
The mood state in depression differs substantially from normal sadness. In fact, many depressed people say they cannot feel sadness, and many people cannot cry when depressed. Being able to cry again often means the depression is improving.

**Marked Loss of Interest or Pleasure in Activities That Used to Be Fun**
When people have just begun to feel depressed or are mildly depressed, they can still enjoy things, and may also be distracted by pleasurable activities. When people are severely depressed, they lose these abilities.

**Weight Loss or Weight Gain**
Many people lose weight when depressed, partly because they lose their appetite. However, one subgroup of patients feels hungrier, and may develop a craving for carbohydrate-rich and fatty foods. This results in weight gain. Metabolism may also increase or slow down, depending on the type of depression; such changes in metabolism can cause either weight loss or weight gain.

**Sleep Problems**
Sleep disturbance is common in depression. Many people suffer from insomnia: they have trouble falling asleep, wake up often during the night or wake very early in the morning. People do not see sleep as being restful, and they may wake up feeling exhausted. Other people oversleep, especially during the day; they are said to have “hypersomnia.”

**Apathy or Agitation**
Many people with depression develop slowed-down movement, speech or thinking.

**Speeded-Up Activity**
People may socialize more than usual at work or school, or may be much more active, with seemingly boundless energy. In the early manic phase, they may be productive, but as symptoms worsen, people are more frantic in their activities and start but do not finish many projects.

**Poor Judgment**
People may not be able to control or plan how they act. They may take part in unusual and risky activities without realizing harmful consequences (e.g., shopping sprees, bad business choices and bad decisions). They may feel more sexual, become more sexually active and take less care in choosing their sexual partners. This increased sexual activity may lead to unwanted pregnancies, sexually transmitted diseases, guilt and disrupted relationships.

**Psychotic Symptoms**
People may experience delusions, or beliefs that are not based in reality. They may hallucinate — most often, they hear voices.

**Hypomania**
The symptoms of hypomania are less severe than those of mania, but may still be disruptive. People may feel happy and have lots of energy, but do not usually get into serious trouble. Hypomania may progress to a full-blown manic episode or a severe depression, and therefore needs treatment.

**Mixed State**
Some patients do not always have “pure” manic or depressive episodes. Instead, they may experience episodes in which manic and depressive symptoms occur at the same time. This is called a “mixed state.” For example, someone in a mixed state can think and speak very rapidly. At the same time, the person may be very anxious and have suicidal thoughts. Mixed states are hard to diagnose and are very painful for the individual.
Depressive symptoms also often include:

• severe anxiety
• worries about small matters
• complaints about physical symptoms, including pain
• many visits to the family doctor for various physical symptoms.

Other Symptoms of a Bipolar Episode

Some patients with bipolar disorder may have problems with movement during their episodes. These disturbances of movement (motor symptoms) occur in up to 25 per cent of depressed patients and up to 28 per cent of patients with mixed or pure manic episodes. These motor problems are called “catatonic symptoms.” Such symptoms vary and may include extreme physical agitation or slowness and odd movements or postures. Patients can’t be slowed down or, on the other hand, they may move so little that they even refuse to open their mouth to eat, drink or speak. This is a serious risk to their physical health. In most cases, patients become free of catatonic symptoms after specific treatment.

There is a risk that people who exhibit catatonic symptoms may be misdiagnosed, because catatonic symptoms have been traditionally associated with schizophrenia, rather than bipolar disorder.

“Comorbidity” and Its Importance

A “comorbid disorder” is an illness or medical condition that occurs together with another illness or medical condition. Comorbid conditions can occur with bipolar disorder — they can start either before a bipolar illness or at the same time. Experts do not know why some disorders co-occur frequently with bipolar disorder and others do not. The severity of the comorbid condition may change over a lifetime, and its symptoms may also vary as the bipolar disorder changes.
For example, one of the most common comorbid conditions is drug or alcohol abuse. People with an alcohol problem may drink too much during mania, or they may experiment with drugs, because they feel free and they are impulsive. They may also drink or do drugs during depressive phases, because alcohol or drugs help them to feel less depressed. The same people may not abuse alcohol or drugs during their well phase.

Other Psychiatric Conditions that often Co-occur with Bipolar Disorder
- panic disorder
- obsessive-compulsive disorder
- binge eating disorder
- drug/alcohol abuse

It is important to diagnose comorbidity in bipolar disorder. Comorbid conditions may cloud the clinical picture and complicate treatment of bipolar disorder. Also, the comorbid conditions are often so severe that they too need treating.

Several factors are involved in causing bipolar disorder, and the precise mechanism is not known. However, there is strong evidence that biological, including genetic, factors play an important role. This does not mean that a person has to inherit the genes: the genes involved may be altered when a person is conceived.

Genes are the blueprint for all cells and their contents. Scientists thus believe that changes to genes can lead to faulty proteins being produced within brain cells. These faulty proteins may then result in bipolar disorder. Researchers today are looking at various proteins that may be affected in bipolar disorder. These include:

- proteins such as those involved in making chemicals in the brain called neurotransmitters
- proteins that use neurotransmitters to make the cell do something
- genes themselves.

We do know that too much stress or difficult family relationships do not cause the illness. However, these factors may “trigger” an episode in someone who already has the illness. Nor is bipolar illness a simple imbalance of neurotransmitters, such as serotonin or dopamine. Yet neurotransmitters may be affected during a flare-up of the illness.

What Is a “Trigger” for a Bipolar Episode?

Not all episodes can be related to any particular trigger, but many can. Triggers are situations that can provoke either mania or depression in someone who has already had an episode of illness. Feeling very stressed or continually losing sleep is an example of this kind of trigger. Other triggers are chemical, and include antidepressants that work “too well” and result in mania; common medications, such as steroids (for instance, prednisone used for treating asthma, arthritis, etc.); and street drugs, such as cocaine and amphetamines.
Treatment of bipolar disorder includes biological treatments (medications) and psychosocial treatments (psychotherapy, rehabilitation). Often both types of treatment are needed, but usually biological treatment is needed first to bring symptoms under control.

**Biological Treatments**

Because bipolar disorder is a biological illness, the main forms of treatment are biological. These consist mainly of medications, but also include other treatments, such as electroconvulsive therapy (ECT) and light therapy.

**Medications**

Medications fall into two broad categories — mood stabilizers and adjunct medications.

**Mood stabilizers**

Mood stabilizers are medicines that help reduce swings in abnormal moods. They also help prevent fresh mood episodes. The first, and most studied, of these is lithium, a naturally occurring salt that has been used for 50 years. Lithium still has a major role in bipolar disorder. Carbamazepine, a medicine first used for epilepsy as an anticonvulsant, is used occasionally. It was found to be a mood stabilizer in the 1970s. Valproic acid (also including its various forms of sodium valproate and divalproex sodium) is another anticonvulsant that has become widely used in the 1990s to stabilize moods. It is used so often because many doctors feel it helps more types of mood swings and symptoms than lithium, and has fewer side-effects than lithium.

However, all of the newer treatments are not necessarily “better” simply because they are newer. For some patients, lithium may be the most effective treatment.

**Adjunct medications**

Adjunct medications are simply other medications that can be used to treat specific symptoms, for example, depression, poor sleep, anxiety and psychotic symptoms. Adjunct medications include antidepressants, anti-anxiety medications, and antipsychotics, or “neuroleptics.” These medications are often only used for the short term. In contrast, mood stabilizers are used for the long term.

**Antidepressant medication**

Antidepressants are medications that were originally found to be useful in treating depression, and more recently have often been found helpful to treat anxiety disorders. The first antidepressant was discovered by accident: patients with tuberculosis in the 1950s were often treated with iproniazid, which was found to elevate mood. Later research resulted in the development of tricyclic antidepressants such as imipramine (Tofranil®) and amitriptyline (Elavil®). These were followed by fluoxetine (Prozac®), the first of the “new” antidepressants, in the 1980s. Currently, there are over 40 antidepressants available, spanning many different classes of medications.

Antidepressants are thought to work primarily by affecting the concentration of neurotransmitters in the brain. Key neurotransmitters that are affected include serotonin, norepinephrine, and dopamine. While antidepressants can be used in bipolar disorder during depression episodes, they must be used with caution since they can also cause a switch into mania and may precipitate a cycle of frequent mood episodes (rapid cycling).

**Anti-anxiety medications**

Anxiety is common in bipolar disorder. Sleep disturbance is also very frequent during an acute episode. Benzodiazepines, a family of medications (the most well known is Valium®) with mild sedating ability, are often prescribed — particularly lorazepam (Ativan®) and clonazepam (Rivotril®). These may be used for short periods without the patient becoming addicted. Clonazepam is particularly useful for treating the excessive energy and reduced sleep of hypomania. For more severe anxiety problems, such as panic attacks, a special type of psychotherapy, known as cognitive behaviour therapy, may be very helpful. It may, in fact, be
needed, because the antidepressants that are also sometimes used to treat anxiety disorders may provoke manic episodes.

**Antipsychotic medication**

Antipsychotic medications are commonly used in bipolar disorder. These medications have powerful sedating effects, which help control mania, and can treat psychotic symptoms. Such symptoms may include delusions of grandeur or persecution, and hallucinations. Traditional antipsychotics, such as haloperidol and loxapine, can also prevent new episodes of mania, but their long-term use may bring serious side-effects, such as tardive dyskinesia, a movement disorder.

Newer antipsychotics are also proving useful in bipolar disorder. These include olanzapine (Zyprexa®), risperidone (Risperdal®), quetiapine (Seroquel®), and clozapine (Clozaril®). The new drugs may work to some extent like mood stabilizers. Research continues to see if these medications can treat not only mania but also depression, and prevent new episodes. These newer medications have fewer side-effects than the old antipsychotics.

**Newer Treatments for Bipolar Disorder, Including “Alternative” Medicines**

Many of the newest medications in bipolar disorder were first developed as anticonvulsants — medications used to treat epilepsy. Most of these are now systematically being tested in clinical trials with bipolar patients. Carbamazepine and valproic acid, both regular mood stabilizers, were developed in this way.

Most recently, the novel anticonvulsant lamotrigine (Lamictal®) has proved effective in bipolar depression and useful in rapid-cycling bipolar disorder, and may become a very common treatment. Gabapentin (Neuroatim®) and topiramate (Topamax®) are newer anticonvulsants with some usefulness in treating bipolar disorder. However, to date, no major studies on these medications have been published.

It is helpful to ask your doctor about new and emerging treatments in bipolar disorder. In some university medical centres, it is also possible to participate in clinical trials of new treatments.

“Natural” remedies may have a role. These include fish oil and inositol, a type of sugar. Yet when these products are sold through health food stores, they are often unreliable. Because they have not been precisely formulated, they cannot be recommended. Furthermore, little research has been done on these products. St. John’s wort has been well studied in unipolar depression (depression without mania). However, it has not been studied in bipolar disorder.

**Electroconvulsive Therapy**

Electroconvulsive therapy (ECT) is perhaps the most controversial and misunderstood of psychiatric treatments, due in part to sensationalized and misleading depictions of the treatment in the popular media. In fact, ECT is a highly effective and safe treatment for both the depressive and manic phases of bipolar disorder, and is sometimes used as a long-term “maintenance” treatment to prevent recurrence of illness after recovery.

**Procedure**

ECT involves administering a brief electrical stimulus through the scalp to the surface of the brain. This stimulus produces an epileptic-type convulsion, lasting typically from 15 seconds to two minutes.

During the treatment, a team of psychiatrist, anaesthetist and one or more nurses are present. The patient is given an anaesthetic intravenously to put him or her to sleep briefly during the treatment. A muscle relaxant is also given to prevent physical injury, by lessening the intensity of muscle spasms that accompany a seizure. Oxygen is administered and heart rate and blood pressure are monitored. Although the anaesthetic lasts only a few minutes, patients feel groggy after an ECT treatment and may rest or sleep for about one hour.
TRANSCRANIAL MAGNETIC STIMULATION

Finally, there is transcranial magnetic stimulation (TMS). TMS is a treatment involving magnetic pulses to the brain. TMS is being tested, but its effectiveness has not yet been proven.

Psychosocial Treatments

Psychosocial treatments include psychoeducation, psychotherapy, support groups and rehabilitation.

PSYCHOEDUCATION

Psychoeducation is a specific term for health education for psychiatric illnesses. All new patients should be routinely treated with psychoeducation. It can also be helpful to give patients psychoeducation periodically throughout their illness. Psychoeducation teaches what causes the illness, how to treat it, how to self-manage the illness to some extent, and how to prevent future episodes.

PSYCHOTHERAPY

Psychotherapy is a general term used to describe a form of treatment that is based on “talking work” done with a therapist. The aim is to relieve distress by discussing and expressing feelings, to help change attitudes, behaviour and habits that may be unhelpful, and to promote more constructive and adaptive ways of coping.

Successful psychotherapy depends on a supportive, comfortable relationship with a trusted therapist. Doctors, social workers, psychologists and other mental health professionals are trained in various models of psychotherapy and work in hospitals, clinics and private practice.

There are many different models of psychotherapy. They fall into two general categories. Short-term structured psychotherapy and long-term psychotherapy. Short-term therapy has a specific focus and the therapist is active and directs the process. On average, the treatment lasts for between 10 and 20 sessions. In

ECT can be given bilaterally (the electric current is applied to both sides of the brain) or unilaterally (only on the right side of the brain). Although bilateral ECT causes more memory disruption than unilateral ECT, it is also somewhat more effective and is usually the preferred choice.

Uses of ECT in bipolar disorder

ECT is the most effective, and possibly the fastest-acting treatment for severe depression, and is particularly helpful for highly agitated or suicidal patients or those with psychotic or catatonic symptoms. Some patients receive ECT early in their episode of illness because of the urgency of their situation or their particular symptoms, while others may prefer to use ECT only after various medications have failed. ECT works well for severe mania as well.

While ECT is highly effective at ending an episode of depression or mania, the benefits may not last more than a few weeks or months following treatment. Therefore, patients usually start or continue treatment with mood stabilizers and/or other medication following a course of ECT. Maintenance ECT can be used in cases where medications have not prevented recurrence of illness, or are intolerable due to side-effects.
long-term therapy the therapist is generally less active and the process is less structured. This treatment usually lasts for a year or more. The aim is to facilitate the patient coming up with his or her own answers.

Psychotherapy is a very helpful treatment. For bipolar disorder, though, it only works as an add-on to medications, not as a substitute. Every patient should get some supportive therapy that involves not only managing medication, but also dealing with the various problems that a person with bipolar disorder may experience. Practical suggestions and emotional support are the main features of supportive therapy.

**Cognitive behaviour therapy**

Cognitive behaviour therapy is an example of a short-term structured psychotherapy that has worked well for many other disorders. It is based on the idea that deeply held beliefs or thoughts influence how we look at ourselves and the world, and have a strong influence on our mood and behaviour. For instance, if we are depressed and think no treatment will help, then we might not bother to seek treatment. This almost guarantees that we will feel worse. Cognitive therapy attempts to identify and change such thoughts and to improve mood and functioning. It is now being tested in bipolar disorder. The early results are promising, both in preventing future episodes and in treating depression.

**Insight-oriented or psychodynamic psychotherapy**

Insight-oriented or psychodynamic psychotherapy is an example of a long-term, unstructured psychotherapy. This therapy reduces distress by helping an individual to gain insight into the underlying motives of his or her overall behaviour. While this is not a specific treatment for bipolar disorder, it can be very helpful as increased self-knowledge and awareness leads to more effective management of the illness.

**Group therapy**

Historically, group therapy has been used successfully to provide elements of support and psychoeducation. Cognitive therapy may also be provided in a group. However, group cognitive therapy has not yet been tested with bipolar patients.

**Family and couple therapy**

Finally, family and couple therapy can be very helpful in addressing problems that may have existed before the illness and have become highlighted, or to deal with issues that have arisen as a result of the illness. The timing, however, is of utmost importance. During an acute episode, the family or spouse should be given only support and education. Formal family or marital therapy should wait until the patient is more stable.

**Self-help support groups**

Self-help support groups can be very important to treatment. A group of people who all have bipolar disorder can accept and understand one another, and can share their struggles in a safe, supportive environment. A strong bond usually develops among group members for the reasons just stated. People who have recently been diagnosed with bipolar disorder can benefit from others who have learned successful coping strategies for managing the illness. These groups are usually organized under the auspices of the local chapters of the Mood Disorders Association (see page 43 for additional information).

**Special Treatment Situations**

**Hospitalization**

During severe episodes of depression or mania, patients with bipolar disorder may need to be hospitalized.

Hospitalization is needed if the illness is out of control and putting patients at risk of serious consequences, for example, due to aggressive behaviour, risk-taking, failing to look after their own basic needs, or suicidal tendencies.

**Voluntary versus involuntary admissions**

Patients are usually admitted to hospital voluntarily. This means that they are free to leave hospital at any time if they so choose. However, in Ontario, as in most other jurisdictions, the law also allows any doctor (not just a psychiatrist)
to admit a patient to hospital involuntarily (sometimes called “certifying” the patient). This can happen if the doctor believes there is a serious risk of the patient or someone else being physically harmed because of the patient’s disorder. If no doctor has seen the patient, families also have the option of asking a justice of the peace to order a psychiatric assessment, and must provide convincing evidence that the patient’s illness represents a danger to the patient or others.

Legal safeguards are in place to protect the involuntary patient’s rights. For instance, a “rights advisor” will visit and ensure that the patient has the chance to appeal the involuntary status before an independent board of lawyers, doctors and laypersons, if the patient wishes.

**Inpatient treatment**

A typical hospital stay may be anywhere from a few days up to several weeks, and rarely, several months. Usually patients are expected (or required, if they are involuntary) to remain on the psychiatric unit for the first few days of their stay. As they recover they may be granted increasing privileges to visit other parts of the hospital or to walk outside. Later they will be given passes to go home overnight or for the weekend.

Patients participate in a variety of group educational and therapeutic programs during the day or evening and also have individual sessions with medical, nursing and other professional staff. Medications may be changed or doses adjusted, and families may be interviewed by medical or social work or other staff.

Discharge planning begins immediately following admission to hospital. Patients should expect to leave hospital as soon as reasonable follow-up arrangements are in place and their symptoms have improved enough to ensure they are able to function safely and care for themselves at home. Staying in hospital after symptoms have improved may not benefit the patient. It may in fact cause difficulties, by reducing the patient’s connection to family and social supports and possibly undermining his or her independent living skills.

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**RECOVERY AND PREVENTING RECURRENCE**

The goal in treating bipolar disorder is to help people get well again. This includes:

- treating symptoms until they no longer cause distress or problems
- improving work and social functioning
- reducing risk of relapse.

**Time Frame for Recovery**

Some people may recover quickly from a manic, hypomanic, mixed or depressive episode. For many others, it is more gradual. Often, it takes a few months for a person’s functioning to return to familiar levels. This may be true even if symptoms of the most recent episode have been fully eliminated. The time needed to recover often frustrates people with bipolar disorder. Health care providers often need to clarify the recovery phase for patients, their families and employers.

A person recovering from a broken leg would increase activities gradually. Similarly, gradually increasing activities after a bipolar episode is advised. This approach allows people to take on responsibilities and build self-confidence more manageable. Some individuals rush back into full, if not increased, activities. They may be trying to convince themselves and others that they are fully recovered. This “flight into health” often exhausts and defeats people. Many individuals who expect a lot of themselves are unhappy with how slowly they recover. They feel demoralized by the delay.

**Recovery is a process that takes time.** After a bipolar episode, people often feel fragile, vulnerable and at risk of more episodes. **These feelings are a normal part of the recovery phase.** It takes some time before a person’s confidence and
If a person is well for a long time, does that mean medication is no longer needed?

No, it is possible that the illness has entered into a quiet period. Or it may imply that the medication is working at preventing symptoms. If the person then stops the treatment, the risk of relapse is high: there is more than an 80 per cent risk of relapse within two years. Relapse may occur even after many years of stability.

Is there a chance of becoming addicted to medications? And can they change personality?

No, people do not become addicted to the main treatments for bipolar disorder. These are mood stabilizers, antidepressants and antipsychotics. There is no evidence at this time that these medications change personality. However, caution is warranted with some anti-anxiety drugs, such as benzodiazepines, if taken for a long period of time.

Do medication side-effects go away if a person takes medication for a long time?

Many side-effects from medication do lessen with time. Other side-effects can be relieved with help from a physician. A physician will monitor not only the side-effects but also the medication dose. In some cases, the physician will monitor the blood level of medication and body organ functioning. With these checks in place, the risk for long-term physical complications from the medications is low. The risks of living with untreated bipolar disorder are much greater.

Beyond Medications: Tips for Preventing Relapse and Promoting Wellness

Many, but not all, people with bipolar disorder can benefit from counselling, psychotherapy or meeting with an occupational therapist, social worker or nurse.
Using such resources can help to find coping strategies to reduce symptoms, effectively cope with day-to-day stress and lower the risk of recurrence. Health care providers should recommend treatment tailored to each individual.

1. **Become an expert on your illness.** Ask your treatment provider about the illness and its treatment. Many resources are available. These include books, videos, support groups and information on the Internet. The quality of information varies. Ask your treatment team to recommend good sources.

2. **Live a healthy lifestyle.** Do not use alcohol and drugs. They increase your risk of relapse of the illness. Eat a healthy diet. Research has shown that exercising regularly can positively affect mood. Develop healthy sleep habits. Watch sleep patterns, particularly when travelling, taking holidays or working long hours. Try to go to bed at the same time each night. Avoid stimulating activities close to bedtime. Plan on paying bills, completing work or having important talks earlier in the evening, or, better still, during the daytime.

3. **You can’t get rid of stress, so find better strategies to cope with stress.** Many individuals use only one coping strategy. Work with your treatment team to identify strategies to more effectively cope with day-to-day stress.

4. **Avoid isolating yourself.** Some individuals with bipolar disorder tend to spend too much time alone. This can add to their feeling depressed, demoralized and sad. A strong social network can be a big support. It can act as a buffer against stressors, or situations that cause stress.

5. **Try to balance your life.** Remember, moderation is key. Divide your time among work, family, friends and leisure activities. A more balanced and satisfying lifestyle can help you effectively cope with stress. It may reduce your risk of relapse.

6. **Monitor your symptoms closely.** Many people with bipolar disorder have a signature pattern of symptoms. That is, their symptoms seem to be similar across episodes. For example, some people have learned to recognize the early phase of an impending relapse. Signs may include: needing less sleep, becoming irritable or feeling that medication is not needed. Monitoring such signs closely and seeking medical attention can effectively stop a full-blown episode. Often, a mood diary can help. Most people experience a variety of feelings — not all shifts in your mood are due to bipolar disorder.

7. **Identify family and friends as support.** Insight is commonly lost early in an impending bipolar episode. It can be helpful for friends or family to recognize typical bipolar symptoms; they can assist you in seeking treatment if necessary.

**Practical Aspects of Recovery**

An episode of either depression or mania usually disrupts daily routines as well as work, school, and home life. People may feel that life will never be the same. They may also feel unable to assume previous responsibilities and involvements. These feelings are natural and understandable. Yet, once properly stabilized on medication, most individuals with a diagnosis of bipolar disorder can return to their previous responsibilities and activities.

Planning appropriate goals and setting priorities are essential to making this transition successful. Each plan and set of priorities is individual. However, it is important to discuss your ideas and concerns with your psychiatrist. Taking on too many or too few responsibilities can have a definite impact on recovery. Sometimes, people are advised to discuss their plans with other professionals, for example, an occupational therapist, social worker or psychologist. Family members may also need to know about your plans and concerns. Family can give important support and feedback as people resume responsibilities. The aim is to get the “just right” type of challenge. This is true whether people are returning to school or work, or taking on roles within their family and community.

**School**

If you are planning to return to school, you should discuss this with your psychiatrist and/or mental health professional (e.g., occupational therapist or social worker). Some people find part-time studies a necessary step. Many people experience
problems with concentration and memory. Look for ways to improve or adjust your study habits. Study for shorter periods of time and avoid noisy or high-traffic areas. An inability to block out the surrounding sights and sounds is common.

Sharing the nature of some of your difficulties with your teacher may be helpful. Many schools and most colleges and universities have a “special needs” office that may also be helpful. A counsellor at this office will ask about the reason for your absence. This information will help the counsellors work with your teachers and instructors. A counsellor can suggest the best change to a course load and responsibilities. Sometimes it may be helpful to give permission to these counsellors to speak with your health care providers.

WORK
Returning to work may also include similar challenges and careful planning. It is important to discuss your plans for work with your psychiatrist. You may also need to discuss your concerns and plans with an occupational therapist who can give you additional advice and support about your return to work.

Gradually assuming your responsibilities by either starting part-time or with a lessened workload is highly recommended. Your health care provider may recommend specific job accommodations to your work responsibilities and schedule that may also be helpful in this transition. Typical job accommodations include: more frequent breaks, time off to attend medical appointments and a change in non-essential job duties.

Educating your employer and co-workers about some of the typical signs of mood changes may be helpful in some cases. However, some people prefer not to discuss their illness with employers. Although this will not allow for the opportunity to ask for any job accommodations, it does not mean that you will be unsuccessful in your transition back to work. Having support outside of work, to discuss your problems and concerns, can be especially important in this situation. Regardless, each situation calls for an individualized plan and support.

HOME AND COMMUNITY RESPONSIBILITIES
Home and community duties may also need to be resumed on a gradual basis. People must find that “just right” challenge of responsibilities and involvements. Reviewing priorities and developing a plan to resume activities may also be necessary. Look at what you can and have been doing, and plan accordingly.

What you are currently able to do may not match what you were able to do in the past. Although this may be frustrating, set daily goals and monitor your accomplishments. Reflecting on and modifying your expectations is often an important part of this process. In the early stages you may need to rely on family members to absorb some of the household and daily responsibilities. As recovery continues, you can gradually resume your responsibilities.

RECOGNIZING AND RESPONDING TO MOOD CHANGES
Learning to recognize and respond to any subtle mood changes is important. This is true when returning to school, work, or home and community involvement. Focusing on ways to concentrate better and work more efficiently may also help. Individuals may benefit, too, from decreasing some of the external stresses in their environment.

DEPRESSION
Typical signs of starting to feel depressed are:

- trouble concentrating and focusing or completing tasks
- lower energy level and confidence
- sensitivity about the comments of others
- increased worry
- doubting the worth of daily involvement in activities
- trouble making fairly simple decisions
- changes in sleep and appetite.
CONCENTRATION
Whether you are feeling depressed or hypomanic, you may have trouble concentrating. At these times, you should:
• discuss your problems with your doctor
• recognize that this will not last
• try harder to write out goals and make plans for yourself
• set goals that have flexible time limits
• make your environment less stimulating
• try to become aware of what times you perform best during the day.

HYPOMANIA
Typical signs of starting to feel hypomanic are:
• decreased need for sleep
• higher energy level and confidence (often includes taking on many tasks)
• trouble settling down to work
• strong feelings or disagreements (more than usual)
• making decisions impulsively (more than usual).

When hypomanic, you may find it helps to:
• recognize some of the symptoms and speak to your doctor to decide if your medications need to be adjusted, or other treatments may be necessary
• look for ways to make your physical environment less stimulating
• consciously try to get enough sleep and to relax enough
• look for ways to protect yourself against yourself, for example, putting away credit cards, avoiding certain social circles
• consider putting off major decisions and cancelling any critical meetings
• plan your day and keep to a small schedule
• set goals to address these mood changes outside work, for example, find how to work off your extra energy safely with hobbies, exercise, etc.
What Happens When Someone You Love Has Bipolar Disorder?

When a family member has a chronic illness, it affects your entire family. It is not just the person with the illness who suffers. This is true of a physical illness, such as diabetes, or a mental illness, such as bipolar disorder. When your relative or partner has a mental illness, you must cope with extra stressors. People are learning more about mental illness and becoming more aware of it. Yet a certain amount of stigma remains. Fearing prejudice, your family may try to deal with mental illness alone. Furthermore, bipolar disorder will affect your relative’s mood and behaviour. At times, your family member’s mood disorder can make him or her less able to manage the illness, and he or she may become less willing to work with you in solving problems.

As a family member, you will likely find both the manic and depressed phases of the illness very distressing. Your family member may have only mild mood swings. If so, you may be able to get through them without too much trouble. If, however, your relative’s mood swings are severe, you will likely find them very hard to handle.

Depression

Watching a loved one struggle with depression can trigger many feelings in those who are close to the person. These feelings may range from sadness, concern, fear, helplessness and anxiety to guilt and anger. All depressive episodes are upsetting. It is likely, though, that your family member’s first episode will be the most confusing. You may not understand what is happening and why your relative is not getting better on his or her own. As a family member, you need information about depression. Without it, you may assume that your relative is lazy; you may give well-meaning advice and become frustrated and annoyed when your relative does not act on it. If your relative or partner talks about suicide, you will understandably live with a lot of worry.

How to Relate to a Depressed Person

Family members often do not know how to talk to a depressed person. They may be afraid to ask too many questions and upset their loved one without meaning to. At the same time, family members do not want the ill person to feel that they are not interested or are avoiding him or her.

Try to support and understand your relative. Be as patient as possible. Just recognizing that depression is an illness can help your relative to feel less guilty about not functioning well.

Tips for Communicating with a Depressed Person:

1. Speak in a calm quiet voice.
2. Focus on one subject at a time. Your family member may have trouble concentrating.
3. Be patient and wait. Your loved one may take a while to respond. Your ability to listen is valuable to your relative or friend. Depression causes people to talk a lot about how bad they feel. Yet they may not be ready to discuss how to solve their problems. Listening and letting the person know, in a neutral way, that you have heard what he or she has said is valuable and supportive. You do not have to offer solutions.

If the person is irritable, you may need to slow down, expect less and use a very non-threatening approach. Neutral comments about the weather, what you are making for dinner or other routine subjects are the safest way to develop a dialogue. Listen for chances to acknowledge or add to your relative’s responses. At these times, talking about important choices or issues is unlikely to produce results. You may need to plan to discuss important issues later.
4. Avoid quizzing people about what made them feel depressed. Do not blame them for the way they feel or tell them to snap out of it. Moderately depressed people may hear what you suggest. Yet they may be unable to act on your advice. Quizzing or blaming them will only make them feel more guilty, lonely and isolated. Often, depressed people do not know what made them depressed or what will help.

5. Pace yourself. If your family member is severely or more chronically depressed, it is normal for you to find his or her company very draining. Brief, frequent contacts with a severely depressed person are often best. If your relative is hospitalized, family members might take turns visiting the patient.

**MANIA**

How a person behaves during a manic episode stirs up intense feelings in everyone, especially family members. You may feel frustrated and annoyed, or you may even feel anger and hatred. The strength of your feelings will depend on how severe the episode is. Particularly frightening in a manic episode is if your family member, as you know him or her, seems to be replaced by a stranger. For example, a reserved, responsible woman can become loud and sexually free; a kind, gentle man can become bossy and cruel.

As well, the manic person usually thinks that he or she is right and everyone else is wrong. This aspect of mania challenges families and others around the manic person. Your family member may take no responsibility for what he or she says or does. As a result, there may be times when you have to bail out your relative. Moreover, your relative can be acutely sensitive to weaknesses in others and can behave in ways that embarrass them. The severely manic individual can easily blow up. Being with someone who is severely manic has been compared to walking in a minefield — one never knows when there will be an explosion. Hardest of all, when your family member is manic, he or she may have no insight into his or her manic behaviour.

If your spouse or partner is manic, you may find it very hard because you, more than anyone, may suffer from his or her anger. You may become a buffer between the person and the community as others demand that he or she be controlled. If your spouse or partner runs up large bills, you may be hounded by creditors. Some severely manic people have extramarital affairs, which they may flaunt. If this happens, you may feel humiliated and betrayed.

Withdrawing from your spouse or partner and considering divorce may seem the only ways out of an intolerable situation. You should not make big decisions, such as whether or not to divorce, when the person is severely ill. The situation will probably change when he or she has recovered.

**HOW TO RESPOND TO A MANIC PERSON**

Early in a manic episode, the individual may be overly happy, energetic and outgoing. Those around the person can easily be caught up in the high spirits. Stay realistic and do not get carried away by this high mood. A person who is manic feeds on attention and conflict. Try to discourage the person from becoming involved in stimulating situations, such as long talks and parties.

Only a small percentage of people with bipolar disorder experience severe mania. In severe mania, the patient may become hostile and suspicious. He or she may even explode verbally and physically. Avoid arguing with someone in this state. The person will only become angrier and may even assault you.

Typically, manic individuals may behave without being aware of or considering the dangers to themselves and others. They may take on risky business ventures, overspend, drive recklessly, etc. You may need to step in. The best way of preventing this kind of behaviour is to plan for it when your relative is well. During periods of stable mood, discuss and set rules that may involve safeguards. For example, consider withholding credit cards, banking privileges and car keys. Hospitalizing a person with mania can save his or her life.
You may see that your family member is becoming hypomanic, that is, acting more energetic than usual, sleeping less, talking a great deal. If so, you must encourage the person to see a doctor at once. That way, your relative can get medication to help calm down and stabilize his or her mood. For some people, hypomania leads to mania. If they are treated when they are hypomanic, they may avoid a full-blown manic episode. Once your partner or relative is manic, he or she may refuse to see a doctor. This is because the person will not think that he or she is ill. Families usually have a very hard time living with a manic person who refuses treatment and who cannot be legally hospitalized. Most jurisdictions in North America have mental health laws that make it hard to hospitalize people against their will. People can only be forced into hospital if they threaten to harm themselves or others, or if they cannot care for themselves.

Most people will agree to go to hospital or to see their doctor. However, if a person refuses, you can then ask a doctor to make a house call and certify that the person must be hospitalized. If this is not possible, and the person is a threat to others or himself, you can get an order for a psychiatric assessment authorizing police to take your relative to hospital.

The police are sometimes needed to get an ill person to hospital. Family members may agonize over whether or not to involve the police. They often feel very guilty about having contacted the police, even when the police were needed to protect the person’s life. Remember, when people threaten suicide, they are usually pleading for help. They should be taken seriously. Suicidal thinking is most often a temporary emotional state. During this phase, a person needs to be kept safe. Similarly, manic episodes can make a person behave dangerously with serious consequences. Manic patients are therefore best treated in hospital.

COMPLIANCE WITH TREATMENT

Some people are very relieved when they are finally diagnosed and get a treatment that stabilizes their moods. For others, however, the road ahead is long and bumpy. Accepting that they have a disorder that must be managed over their lifespan may be traumatic. Some people must endure several manic or depressive

TIPS FOR COMMUNICATING WITH A MANIC PERSON

1. Reduce stimulation. People with mania are easily overstimulated. You may need to have fewer people visit at the same time. Or you may need to lessen noise and activity in the house.

2. Have brief conversations.

3. Deal only with immediate issues. Do not try to reason or argue.

4. Discourage discussing feelings.

5. Try not to be authoritative. Yet be firm, practical and realistic.

6. Do not jump to the person’s demands.

7. Do not get caught up with the person’s euphoria, or unrealistic expectations.

8. Do not try to convince the person that his or her plans are unrealistic. At the same time, take steps to ensure his or her safety (e.g., removal of car keys or credit cards).

GETTING TREATMENT FOR YOUR FAMILY MEMBER

A partner or relative who is moderately depressed will probably agree to medical treatment without needing too much encouragement. Yet a person who is severely depressed and suicidal may refuse to be treated. This happens because the person feels so hopeless and worthless. In this case, you or someone the person trusts should insist that he or she see the doctor, even if the person protests. If your partner or relative does not have a doctor, go to the emergency department of the nearest hospital.
episodes before they consistently accept help from doctors and therapists. Mild mania can be seductive to some people because it often includes feeling happy, more confident, more energetic and more creative. It may therefore provide an ongoing lure to stop them from taking their medication.

As a family member, you may find it very hard to watch this process. You may try repeatedly to convince your relative to “take your medication” or “go and talk to your doctor.” Trying continually to convince and coax can lead to heated arguments and power struggles. You may be very close to the person with bipolar disorder and yet feel that your views are unwelcome. In this case, it is sometimes more effective to have another trusted person approach your relative.

**Care for Families**

When someone has a serious illness, family members naturally feel worried and stressed. They spend time comforting or helping their loved one. As a result, they may give up their own activities. Unsure of how others may respond to their ill partner or relative, family members may also avoid having friends visit their home. Over time, they may lose touch with their own network of friends. Or they may find that caring for their depressed/manic family member has replaced their own routines and activities. Often, people take a long time to realize how emotionally and physically drained they have become. This stress can lead to sleeping badly, or feeling exhausted or irritable all the time.

**Recognize these signs of stress in yourself and look after your own physical and mental health.** Finding your own limits and making time for yourself are key to “self-care.” Try to create a support system of friends and relatives you can rely on. Think about people you might want to confide in. Mental illness is hard for some people to understand. Be selective and confide only in people who will support you.

Consider having your own professional support. You could also join a self-help organization or relative support program. Local hospitals or community mental health clinics may offer such programs. Keep up your interests outside the family and apart from your ill relative. Acknowledge and accept that at times you will feel negative about the situation. These feelings are normal — try not to feel guilty about them.

**Being Ready for a Relapse or Crisis**

Families often avoid talking to their relative about relapses or crises. They fear that talking about a crisis will bring one on, or they simply do not want to upset their relative. As well, everyone hopes that the last crisis was an isolated incident that will not recur. The best way to handle a crisis or possibly avoid it is to know what to do before it happens. While focusing on wellness, some planning for recurrence can help both the ill person and the family to feel more secure.

When your relative or partner is well, plan what to do if he or she should become ill:

- Could you both visit the physician to discuss your relative’s condition and how to deal with a possible crisis?
- Do you have advance permission to contact your relative’s doctor if your relative falls ill?
- Has your relative consented to your taking him or her to hospital? If so, which hospital has your relative chosen?
- If your relative becomes unable to decide on treatment, does he or she agree that you can make that decision?

You may want to write down the terms that you and your partner or relative have agreed on. This can help to ensure that the terms are followed. Building a good relationship with the treating physician and having a pre-arranged emergency plan can also help to avoid a crisis.
Planning should include how to deal with suicidal behaviour. It should also cover how to prevent harmful results of manic behaviour, such as overspending or reckless driving.

5. Remember your own needs. Try to:

- take care of yourself
- keep up your own support network
- avoid isolating yourself
- acknowledge, within your family, the stresses of coping with bipolar disorder
- share the responsibility with others, if possible
- stop bipolar disorder from taking over family life.

6. Support recovery from an episode by recognizing that it is slow and gradual. Know that your family member needs to recover at his or her own pace. Try not to expect too much but avoid being overprotective. Remember that stabilizing mood is the first step towards a return to normal functioning. Try to do things with your relative rather than for him or her. That way, your relative will slowly regain self-confidence.

7. View your family member’s bipolar disorder as an illness, not a character flaw. Treat your relative normally once he or she has recovered. At the same time, watch for possible signs of recurrence. In a caring way, point out the early symptoms and suggest a talk with the doctor.

8. Learn, with your family member, to distinguish a good day from hypomania and a bad day from depression. Like everybody else, people with bipolar disorder have good and bad days that are not part of their illness.
8 EXPLAINING BIPOLAR DISORDER TO CHILDREN

School-aged children can process more information than younger children. Yet they may be overwhelmed by details about medications and therapies.

“You know how sometimes you feel very happy or very sad? Well, Daddy has a kind of sickness where he sometimes has those same feelings, but they are much stronger and can last a really long time. Those strong feelings can make him say or do things that can be upsetting. He doesn’t really know when it will happen, but he takes some medicine to help make him feel better.”

Teenagers can generally manage most information. Often, they need to talk about their thoughts and feelings. Teenagers worry a lot about what other people, especially their peers, will think of themselves and their families. They may ask about genetics. They may also wonder how open they should be about the situation and worry about the stigma of mental illness. Sharing information encourages talking further.

It is helpful to cover three main areas:

CHILDREN MUST KNOW THAT THE FAMILY MEMBER HAS A SICKNESS CALLED “BIPOLAR DISORDER.”
The parent or family member behaves this way because he or she is sick. Bipolar disorder makes people feel one of two ways. They may be very depressed, or sad, sometimes for no reason. They may cry a lot, sleep all day and have trouble eating or talking to people. At other times, they can become very loud and happy. Small things can irritate them and make them angry.

CHILDREN NEED TO KNOW THAT THEY DID NOT CAUSE THE ILLNESS.
Children need reassuring that they did not make the parent or family member sad, angry or happy. They need to be told that their behaviour did not cause their parent’s emotions. Children think in concrete terms. If a parent is sad or angry,

Explaining mental illness or bipolar disorder to children can be awkward and difficult. To protect their children, the affected and well parents may say nothing and try to continue with family routines as if nothing were wrong. This strategy may work in the short term. Over the long term, though, children can feel confused and worry about how their parent’s behaviour has changed.

Children are sensitive and intuitive. They quickly notice when someone in the family has changed, particularly a parent. The atmosphere in the family may not encourage talk about this subject. If so, children will draw their own, often wrong, conclusions. Young children, especially those in preschool or early grades, often see the world as revolving around themselves. If something bad or unpleasant happens, they assume they caused it. For example, a child may accidentally break something valuable. The next morning, the parent may seem very depressed. The child may then assume that breaking the object caused the parent’s depression.

Children need to have illnesses explained to them. It is best to give them as much information as they are mature enough to understand. For example, toddlers and preschool children understand simple, short sentences. They need concrete information and not too much technical language.

“Mommy is sick and feels sad — just like when you have a cold, you don’t feel well.”

“Sometimes when Daddy is feeling sick, he gets tired and mad. He will feel better later.”

It is best to explain simply and then try to normalize the situation. Moving on to do something special that the child enjoys can make things feel better for the child.

“Mommy is sick and feels sad — just like when you have a cold, you don’t feel well.”

“These feelings can make him say or do things that can be upsetting. He doesn’t really know when it will happen, but he takes some medicine to help make him feel better.”

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Once recovered, the parent who was ill can help by explaining, in simple terms, his or her behaviour to the children. The recovered parent may need to plan some special times with the children. Such times re-establish the relationship and reassure the children that the parent is again available and interested in them.

Children can easily feel they did something to cause this, and then feel guilty. Bipolar disorder needs to be explained as an illness. It just like having the chicken-pox or a bad cold.

**Children should be reassured that it is not their responsibility to make the ill person well.**

Children need to know that the adults in the family and other people, such as doctors, are working to help the affected person. It is the adults’ job to look after a person with a mood disorder. Children need the well parent and other trusted adults to act as a protective buffer between them and the parent’s symptoms of depression and mania. It is very hard for children to see their parents distressed or in emotional pain. In the same way, children have trouble coping with the irritability of a parent struggling with mania. Talking about what they have observed and experienced with someone who understands the situation can help sort out the child’s confused feelings.

Many children are scared by the changes they see in their parents. They miss the time previously spent with this parent. Taking part in activities outside the home helps because children are exposed to other healthy relationships. In time, as the ill parent recovers, gradually resuming family activities can then help mend the relationship between the children and the affected parent.

Both the ill and the well parents should talk with the children about explaining the illness to people outside the family. Support from friends is important. However, bipolar illness can be hard to explain, and some families are concerned about the stigma of mental illness. Each family must choose how open it wants to be.

Finally, some parents struggling with bipolar depression may not be able to tolerate their children’s noise and rowdy play, even though such disturbances are part of children’s everyday activities. Special measures may be needed to buffer the ill parent from situations that may lead him or her to be irritable and abrupt with the children. At times, children may need to play outside the home. Or the ill parent may need to rest for part of the day in a quiet area of the house.
RESOURCES

Mood Disorders Associations

Mood Disorders Associations are non-profit, self-help organizations committed to improving the quality of life for people with mood disorders, their families, and their friends. They accomplish this through mutual support, information, and education. Most chapters offer:

- regular peer support groups and support groups for families
- telephone information and support
- information meetings with experts
- a newsletter
- a resource centre and library.

Provincial Associations

The following provincial associations can help you locate a chapter near you:

Mood Disorders Association of British Columbia
201 – 2730 Commercial Drive
Vancouver, BC V5N 5P4
(604) 873-0103

Depression and Manic Depression Association of Alberta
Box 64064
1528 – 107 Avenue
Edmonton, AB T5K 2J5
1-888-757-7077

Mood Disorders Association of Manitoba
4 – 1000 Notre Dame Avenue
Winnipeg, MB R3E 0N3
(204) 786-0987

In the United States

The following organizations have local chapters and can help you locate local chapters and information:

National Depressive and Manic Depressive Association
501 – 730 N. Franklin Street
Chicago, IL 60610-3526
1-800-82-NDMDA (1-800-826-3632)

National Alliance for the Mentally Ill (NAMI)
1015 – 200 N. Glebe Road
Arlington, VA 22203-3754
1-800-950-NAMI (1-800-950-6264)
GLOSSARY

ADJUNCT MEDICATION — medicine that complements a main medication.

AGITATION — a severe inner restlessness that is often accompanied by anxiety. Patients typically cannot sit still; they may pace and wring their hands.

“ALTERNATIVE” MEDICINES — for bipolar disorder, these include “natural remedies,” such as fish oil and inosital (a kind of sugar). Little research has been done on these products.

ANTI-ANXIETY MEDICATION — a type of adjunct medication used to treat anxiety. Examples include benzodiazepines, such as lorazepam (Ativan®) or clonazepam (Rivotril®), and some antidepressants.

ANTIDEPRESSANT MEDICATION — medication used to treat the symptoms of depression.

ANTIPSYCHOTIC MEDICATION — formerly called neuroleptic medication. These agents quickly control mania and treat psychotic symptoms. Antipsychotics can also prevent new attacks of mania.

ANXIETY — excessive worry, fear and uncertainty that are hard to control. Anxiety is common in bipolar disorder.

BENZODIAZEPINES — a group of anti-anxiety medications that share a similar chemical structure. Some common benzodiazepines are diazepam (Valium®) and lorazepam (Ativan®).

BIPOLAR DISORDER — also known as manic-depressive illness. A disorder characterized by mood swings from depression to mania.

BIPOLAR-I DISORDER — a type of bipolar disorder in which people experience full manic or mixed episodes.

REFERENCES


**BIPOLAR-II DISORDER** — a type of bipolar disorder in which people experience only hypomania and depression.

**CATATONIC SYMPTOMS** — Patients who become catatonic have trouble with movement — they may experience extreme physical agitation or slowness and odd movements or postures.

**COGNITIVE BEHAVIOURAL THERAPY (CBT)** — a type of talk therapy where patients learn to recognize their own negative or disruptive thought patterns. Patients then try to change the behaviours that result from these thoughts. CBT is beginning to be tested in the treatment of bipolar disorder, with promising early results.

**COMORBID DISORDER** — a medical condition that often accompanies, or co-occurs with, another disorder; for example, drug or alcohol abuse, panic disorder, obsessive-compulsive disorder or binge eating disorder can co-occur with bipolar disorder.

**COMPLIANCE** — a patient’s full participation in the treatment prescribed by the physician; for example, taking medication as directed and attending therapy sessions.

**CYCLE** — the time from the start of one episode until the start of the next.

**DELUSION** — a false, fixed belief not shared by other people in the same culture; for example, a person may believe that his or her thoughts are controlled by outside forces. There are various types of delusions, such as paranoid (with feelings of suspicion) and grandiose (with feelings of excessive self-importance).

**DEPRESSION** — an episode characterized by a loss of energy, feelings of worthlessness and loss of interest in things that usually bring pleasure (food, sex, work, friends and entertainment). Patients may think often about death or suicide. Physicians diagnose depression when at least five of a group of symptoms have lasted for at least two weeks.

**DOPAMINE** — a type of neurotransmitter, or brain chemical, thought to be affected in a person with mental illness. Making dopamine more available is one way to treat depression; blocking dopamine helps treat psychosis.

**ELECTROCONVULSIVE THERAPY (ECT)** — a treatment procedure for severe depression and severe mania. ECT involves passing a controlled electric current between two metal discs applied on the surface of the scalp.

**EPISODE** — a period of illness. This can include depression, hypomania, mania or a mixed state.

**GROUP THERAPY** — therapy for a number of patients together. Group therapy has been used successfully to give patients support and psychoeducation.

**HALLUCINATION** — a false experience involving the senses, such as seeing, hearing, tasting, smelling or feeling something that does not really exist.

**HYPERSOMNIA** — the condition of sleeping too much, especially during the day. Hypersomnia can be a symptom of bipolar disorder.

**HYPOMANIA** — a state characterized by a high mood and overactivity. It is not as extreme as mania.

**INSOMNIA** — the condition of not being able to fall asleep, or of waking too soon or repeatedly. Insomnia can be a symptom of bipolar disorder.

**LIGHT THERAPY** — Light therapy is a form of treatment involving exposure to a specific type of light for 30 minutes to one hour daily, for several weeks. This light is usually provided by a special light box, and is useful for the treatment of seasonal depressions and occasionally for other types of depression.

**MAOI** — MAOI stands for Monoamine Oxidase Inhibitor, a class of antidepressants that work by reducing the effects of the enzyme monoamine oxidase.
PANIC DISORDER — an anxiety disorder characterized by attacks of severe anxiety, terror or fear.

PSYCHOEDUCATION — a process that allows people to recognize and learn how to manage their psychiatric illness.

PSYCHOSIS — a term once used for any mental disorder. Psychosis now refers only to disturbances that cause the personality to disintegrate and the person to lose contact with reality.

PSYCHOTHERAPY — a general term used to describe a form of treatment based on talking with a therapist. Psychotherapy aims to relieve distress by discussing and expressing feelings. The goal is to help the patient change attitudes, behaviour and habits, and develop better ways of coping.

RAPID CYCLING — Individuals are said to be rapid cycling if they experience more than four episodes a year. Only 20 per cent of patients experience rapid cycling.

RECOVERY/RECOVERY PHASE — the period when a person is getting over an episode of illness. The patient often feels fragile, dependent and at risk of other episodes.

RELAPSE — return of the symptoms of an illness after the patient has seemingly responded to treatment, but before the symptoms have fully gone.

SELECTIVE SEROTONIN REUPTAKE INHIBITORS (SSRIS) — a class of drugs used to treat depression and related disorders. SSRIs inhibit the reuptake of serotonin (a neurotransmitter). SSRIs have revolutionized the treatment of depression since the late 1980s because they are very effective and have fewer side-effects than do older antidepressants.

SIDE-EFFECTS — the extra effects of a drug treatment that come with the desired effects. Usually side-effects are unwanted, and can include nausea, headaches, constipation and problems with sexual function.
**STRESSORS** — situations that cause stress.

**SUPPORT GROUP** — a group of people who have a common interest or situation, such as a diagnosis of bipolar disorder, who meet regularly to share ideas, feelings and community resources information.

**TARDIVE DYSKINESIA** — a brain disorder in which the patient experiences involuntary, or unintended, movement of the face and jaw. Tardive dyskinesia can be a side-effect of long use of traditional antipsychotic medications.

**TRANSCRANIAL MAGNETIC STIMULATION (TMS)** — a treatment involving magnetic pulses to the brain. TMS is being tested, but its effects on bipolar disorder are not proven.

**TRICYCLIC ANTIDEPRESSANTS (TCAS)** — a class of older drugs used to treat depression and other disorders.

**TRIGGER** — a situation that can cause either mania or depression in a person who has already had an episode of illness. Stress, sleep loss, steroids and street drugs are some of the triggers for bipolar disorder.

**UNIPOLAR DEPRESSION** — one or more major depressive episodes, but without mania or hypomania.
A Pan American Health Organization / World Health Organization Collaborating Centre

For information on other Centre for Addiction and Mental Health resource materials or to place an order, please contact:

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Centre for Addiction and Mental Health
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Toronto, ON M5S 2S1
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Tel.: 1 800 661-1111 or 416 595-6059 in Toronto
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Web site: www.camh.net

Bipolar Disorder

An Information Guide

ISBN 0-88868-387-1
The Role Checklist

Background

Within the occupational behavior tradition, roles are characterized as critical determinants of productivity. Occupational roles organize behavior by contributing to one's personal identity, conveying social expectations for performance, organizing use of time, and including the individual within the social structure. The occupational therapist’s unique view of disability involves understanding how illness or injury affects occupational role performance. Successful adaptation after illness or injury may depend on a person's ability to competently resume or to establish new occupational roles.

The Role Checklist was designed to elicit information about a person's occupational roles. Occupational roles consist of both playful and productive behaviors. Playful behaviors are characterized as "non work" such as hobbies, sports, or social recreation. Productive behaviors contribute some service or commodity that others need or desire.

The Role Checklist has been translated into ten languages (Arabic, Dutch, French, German, Japanese, Portuguese, Spanish, Swedish, Chinese, & Hebrew) for international use. It is a reliable and valid assessment tool that provides:

1. Data on individuals' perception of their participation in roles throughout their lifespan.
2. Data regarding the degree to which each role is valued.
3. Supplemental information regarding an individual’s capacity to maintain a balance among roles.

Description of the Role Checklist

The Role Checklist is a written inventory, requiring approximately fifteen (15) minutes to administer, and is appropriate for use with an adolescent, adult, or elderly population. It is divided into two parts. Part 1 assesses, along a temporal continuum, the major occupational roles that organize an individual's daily life. Part 2 identifies the degree to which each occupational role is valued.

The occupational roles included in the Role Checklist are: student, worker, volunteer, care giver, home maintainer, friend, family member, religious participant, hobbyist/amateur, and participant in organizations. There is also an "other" category where individuals can enter additional roles not listed. It should be noted that the role definitions include examples that are not meant to be all encompassing. The intent of the checklist is to identify roles with occupational components that serve to organize an individual's daily life. Thus, reference to frequency of performance is included in role definitions. For example, the role of family member refers to spending time or doing something, at least once a week, with a family member such as a spouse, child, parent, or other relative. The key phrase is once a week. People may view themselves as
family members, but their family may reside out of town resulting in infrequent contact. Consequently, that role is not available to organize present daily life.

**Administration of the Role Checklist**

Instruct individuals to complete the demographic information at the top of the checklist. Remain with them until the checklist is completed.

**Part 1**

1) Ask them to read the instructions.
2) Inquire if they understand the instructions and answer any questions pertaining to the administration of Part 1.
3) Define the time frames as follows:
   a) “Present refers not only to today, but also includes the previous seven days.”
   b) “Past refers to the period of time up until seven days ago.”
   c) “Future is anytime from tomorrow onward.”

**Part 2**

1) When individuals have completed Part 1, ask them to read the instructions for Part 2.
2) Inquire if they understand the instructions and answer any questions pertaining to the administration of Part 2.
3) Define "valuable" as follows:
   "Valuable refers to the worth you place on each role, that is, how important or desirable the role is to you."

**Recommended Reading**

The following book by Dr. Gary Kielhofner discusses the theoretical framework upon which the Role Checklist was developed and presents numerous cases in which the checklist was used clinically.


**Publications using the Role Checklist**


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5/04
# ROLE CHECKLIST

**NAME____________________________________________ AGE_________ DATE_________**

**SEX:**
- ☐ MALE
- ☐ FEMALE

**ARE YOU RETIRED?**
- ☐ YES
- ☐ NO

**MARITAL STATUS:**
- ☐ SINGLE
- ☐ MARRIED
- ☐ SEPARATED
- ☐ DIVORCED
- ☐ WIDOWED

The purpose of this checklist is to identify the major roles in your life. The checklist, which is divided into two parts, presents 10 roles and defines each one.

## PART I

Beside each role, indicate, by checking the appropriate column, if you performed the role in the past, if you presently perform the role, and if you plan to perform the role in the future. You may check more than one column for each role. For example, if you volunteered in the past, do not volunteer at present, but plan to in the future, you would check the past and future columns.

<table>
<thead>
<tr>
<th>ROLE</th>
<th>PAST</th>
<th>PRESENT</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>STUDENT: Attending school on a part-time or full time basis.</td>
<td></td>
<td></td>
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<td>WORKER: Part-time or full-time paid employment.</td>
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<td>VOLUNTEER: Donating services, <strong>at least once a week</strong>, to a hospital, school, community, political campaign, and so forth.</td>
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<td>CARE GIVER: Responsibility, <strong>at least once a week</strong>, for the care of someone such as a child, spouse, relative, or friend.</td>
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<td>FRIEND: Spending time or doing something, <strong>at least once a week</strong>, with a friend.</td>
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<td>FAMILY MEMBER: Spending time or doing something, <strong>at least once a week</strong>, with a family member such as a child, spouse, or other relative.</td>
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PART II

The same roles are listed below. Next to each role, check the column which best indicates how valuable or important the role is to you. Answer for each role, even if you have never performed or do not plan to perform the role.

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