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Life Care Planning for People with Severe and Persistent Mental Illness: An Overlooked Practice Setting?

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Abstract. *Severe and persistent mental illness may be an untapped resource for life care planners. Such illnesses are often chronic and debilitating, requiring a complex and comprehensive treatment plan. Treatment usually involves pharmacotherapy as well as psychotherapeutic interventions (i.e., individual therapy, psychoeducation, vocational counseling). Comorbid conditions such as substance abuse are common among individuals with mental illness and present increased challenges for effective treatment and rehabilitation. This article explores two major mental illnesses, bipolar disorder and schizophrenia, and preliminary considerations for life care planning within this population.*

Key Words: life care planning, severe mental illness, schizophrenia, future care, bi-polar, manic-depressive, rehabilitation of mental illness.

Introduction

A review of three well-known books reveals that life care planning has traditionally focused on physical disabilities, with little information available regarding life care planning for persons with psychiatric illnesses (Deutsch & Sawyer, 2002; Weed, 1999; Weed & Field, 2001). As a society, the widespread impact of mental illness on economics and productivity has been largely ignored. Mental illness affects about 1 in 5 adults or about 22.1% of Americans age eighteen and older (Reiger, Narrow, Rae, Mandersheid, Locke, & Goodwin, 1993), and it is estimated that 4-5 million people in the United States are diagnosed with severe and persistent mental illness (SPMI) (Garske, 1999). SPMI is generally defined in terms of diagnosis, degree of disability, and expected duration of illness. Mental illnesses such as bipolar disorder (previously known as "manic-depressive illness") and schizophrenia are categorized as SPMIs due to their chronic, debilitating course. SPMIs have a devastating impact on all areas of life including interpersonal relationships, vocational and educational pursuits, and independent living and life care planning within this population can be considered an untapped but needed resource. As with other disabilities, it is vitally important for the life care planner to understand the complexity of SPMI, including the symptoms, course of illness, and both pharmacologic and psychotherapeutic treatments. This article will serve as an overview of bipolar disorder and schizophrenia, followed by important issues to consider when preparing life care plans for individuals with SPMI. A more in-depth review can be found in the *Life Care Planning and*

Case Management Handbook, 2nd edition (Weed, in press).

Understanding Bipolar Disorder

The Diagnostic and Statistical Manual of Mental Disorders, IV, Text Revision (DSM-IV-TR) identifies four bipolar disorders based on diagnostic criteria: bipolar I, bipolar II, cyclothymia, and bipolar disorder not otherwise specified (APA, 2000). Bipolar I will be the focus of this article and is distinguished from the other bipolar disorders by the presence of mania. The DSM-IV-TR defines mania as the presence of elevated mood, pressured speech, distractibility, racing thoughts, grandiosity, decreased need for sleep, impulsivity, psychomotor agitation, or increases in goal directed activities (APA, 2000). Clients experiencing mania often have poor judgment, little insight into their behavior, and do not seek treatment. People with bipolar disorder also experience periods of debilitating depression or a mixed state where mania and depression are present at the same time. During these times, the individual with bipolar disorder is particularly vulnerable to suicide and the completed suicide rate for bipolar disorder is estimated at 12-19% (Simpson & Jamison, 1999). Complicating the clinical picture, psychotic features (i.e., hallucinations, delusions) may be present in both manic and depressive episodes, presenting a more severe course of illness.

The lifetime prevalence rate of bipolar I disorder is estimated at 0.4-1.6% (APA, 2000). People typically develop bipolar disorder sometime between adolescence and early adulthood, with a mean age of onset at 21 years old (Robins & Reiger, 1991). As a result, individuals with bipolar disorder often do not experience age-appropriate milestones in academics, vocational pursuits, and interpersonal relationships. Hirschfeld and colleagues (2003) report that 69% of individuals with bipolar disorder are misdiagnosed and close to half experience a significant time lapse (from several months to 5 years) between seeking initial treatment and receiving the correct diagnosis. This delay in appropriate treatment may contribute to further deterioration of functioning and overall poorer outcomes. Like many other psychiatric and medical conditions, bipolar disorder is most likely caused by a combination of genetic predisposition and environmental influences (Rush, 2003).

Comorbid Conditions in Bipolar Disorder

Common comorbid conditions found in bipolar disorder include substance abuse, personality disorders, and anxiety disorder. It is estimated that 46% of individuals with bipolar disorder abuse alcohol or have alcohol dependence, compared with a rate of 13% in the general population (Reiger, Farmer, Rae, Locke, Keith, Judd, & Goodwin, 1990). Additionally, 41% abuse or are dependent on other drugs, while the incidence rate in the general population is 6% (Reiger, et al., 1990). Comorbid substance abuse is associated with more severe mood episodes, decreased periods of remission, increased rates of suicide, and overall poorer outcomes (APA, 2002). Personality disorders are present in 28.8% of individuals with bipolar disorder and are associated with more severe residual mood symptoms (George, Miklowitz, Richards, Simoneau, & Taylor, 2003). A recent study reports that 24% of individuals with bipolar disorder have a comorbid anxiety disorder (Henry, Van den Bulke, Bellivier, Etain, Rouillon, & Leboyer, 2003). Comorbid anxiety disorders are more common in individuals with depressive temperaments and contribute to a decreased response to pharmacologic

interventions (Henry, et al., 2003). Comorbid conditions complicate the clinical picture of bipolar disorder and may require additional targeted interventions. Ideally, treatment for such conditions would occur in conjunction with bipolar treatment, especially when comorbid substance abuse is present.

Treatment of Bipolar Disorder

There is no cure for bipolar disorder, but the symptoms can be managed through a combination of pharmacologic and psychotherapeutic interventions. Medications are used to treat acute manic symptoms, alleviate depression, and to prevent future episodes. As of May 2003, only three agents are approved by the Food and Drug Administration for the treatment of bipolar disorder: lithium, valproate, and olanzapine (personal communication, K. Littrell, June 1, 2003). These medications are considered "mood stabilizers," although olanzapine is also an antipsychotic. Many other types of medications are often prescribed to treat bipolar disorder including antipsychotics (especially when psychotic features are present), antidepressants, benzodiazepines/tranquilizers, and anticonvulsants.

Medication side effects are an important issue to consider because they contribute to a lower quality of life and poorer outcomes for individuals with bipolar disorder. Additionally, individuals with bipolar disorder may not take their medications as prescribed because of side effects. It is estimated that 64% of individuals with bipolar disorder are medication noncompliant (Li, McCombs, & Stimmel, 2002). Medication noncompliance is clearly associated with increased risk of relapse and rehospitalization. Finding an effective medication regimen with manageable side effects remains a challenge for clinicians, but newer medications show promise.

Psychotherapeutic interventions include psychoeducation and individual, family, and group therapy. Such interventions are not limited to out-patient treatment. Assisting hospitalized individuals with SPMI develop realistic life goals may increase their feelings of self-worth and control over their lives (Ng & Tsang, 2002). Psychoeducation topics include identifying symptoms, medication management (including side effects), and preventing relapse and rehospitalization. Similar to people with physical disabilities, individuals with bipolar disorder may benefit from therapy that targets issues such as acceptance of the illness, coping with symptoms, dealing with stigma and discrimination, and ways to improve interpersonal and vocational functioning. Research is limited in regards to the efficacy of various psychotherapeutic interventions and their impact on outcomes.

Costs of Bipolar Disorder

There are many issues to consider when examining the costs of bipolar disorder. Chronicity and severity of illness are important factors when establishing expense estimates. Begley and colleagues (1998) report the costs of a single manic episode and chronic episodes at $11,720 and $624,785, respectively and the most costly intervention in the treatment of bipolar disorder is hospitalization. All treatment modalities share the goal of reducing relapse and rehospitalization, and most individuals will need a combination of various medications and psychotherapeutic interventions over the course of their lifetime. See Tables 1 and 2 for estimated treatment costs. Factors such as comorbid conditions and medication non-compliance effect treatment costs. While newer medications may be more expensive, they may result in reduced overall treatment costs due to increased efficacy, reduced side effects, and

Table 1. Commonly Prescribed Medications for Severe and Persistent Mental Illness

Medication	Targeted Symptoms	Estimated Cost Per Month
Anticonvulsants/Mood stabilizers (e.g., Lithium, Depakote, Topamax, and Lamictal. Olanzapine is mood stabilizer and antipsychotic).	Bipolar disorder: mania, depression, relapse prevention. Schizophrenia: aggression, hostility, mood instability.	$50-200 Lab costs (i.e., serum blood monitoring) = $100-150/lab
Antipsychotics (e.g., Haldol, Thorazine, Stelazine, Clozapine, Olanzapine, Risperidone, Quetiapine, and Ziprasidone)	Bipolar disorder: psychotic symptoms, mood instability. Schizophrenia: psychosis, relapse prevention.	Conventional = $60-100 Atypical = $200-500
Antidepressants (e.g., Paxil, Elavil, Effexor, and Prozac)	Depression/anxiety	$100-250
Benzodiazepines (e.g., Xanax, Valium, and Ativan)	Bipolar disorder: mania, anxiety. Schizophrenia: aggression, hostility, anxiety.	$90
Anticholinergics (e.g., Congentin, Artane, and Benadryl)	Use to treat or prevent side effects of antipsychotics (i.e., EPS, TD).	$20-150
Medication Organizer	Assists in taking medications as prescribed.	Less than $5. Replace as needed.

Table 2. Psychotherapeutic Interventions for Severe and Persistent Mental Illness

Therapy	Target Symptoms/ Purpose	Average Base Cost Per Session
Psychiatrist	Medication management.	$100
Individual	Coping skills, adjustment issues, reality testing, relapse prevention, depression, anxiety.	$100
Therapy Group	Same as above, peer support.	$40
Marriage and/or Family	Relapse prevention, crisis planning, adjustment issues.	$125-150
Psychoeducation	Symptoms and course of illness, medication management, relapse prevention, health education.	$30
Rehabilitation Counseling	Assessment of vocational potential, supported employment.	$75 (average)
Support Group	Peer support, socialization.	$0-30

Base costs established by averaging the 2003 Georgia Medicare Fee Schedule with a survey of Georgia mental health treatment centers. The base costs of psychotherapeutic interventions are typically lower in the mental health population than in other populations.

improved compliance (Namjoshi, Rajamannar, Jacobs, Sanger, Risser, Tohen, Breier, & Keck, 2002). More research is needed to better quantify the effect of both pharmacologic and psychotherapeutic interventions on outcomes and reduction in overall treatment costs.

Understanding Schizophrenia

Schizophrenia is characterized by psychosis or a break with reality. The DSM-IV-TR classifies schizophrenia into different subtypes based on symptoms, including paranoid, disorganized, catatonic, undifferentiated, and residual (APA, 2000). Symptoms of schizophrenia are divided into two general categories: positive and negative. Positive symptoms are distortions of normal experience and include hallucinations and delusions. The most common type of hallucination is auditory, usually in the form of hearing voices. Voices are often negative and persecutory, and the individual may perceive them as all-knowing entities that monitor one's actions. Delusions are false, often irrational beliefs that typical fall into the following categories: paranoid/persecutory, grandiose, religious, referential, and somatic. Some examples of delusions are believing that other people can hear one's thoughts, believing one is a religious prophet, or that one's food is being poisoned. Both delusions and hallucinations severely impact normal functioning. Negative symptoms represent a loss in normal functioning and include social withdrawal, loss of the ability to feel pleasure or "empty" feelings, flat affect or reduction in facial expressions of emotion, and lack of will, drive, or motivation. Negative symptoms are more difficult to evaluate due to contributing factors such as depression, medication side effects, and unstimulating environments. Another important category of symptoms is cognitive dysfunction, characterized by impairments in organization skills, memory, attention, and concentration. In the author's experience, the severity of cognitive dysfunction varies from individual to individual, but is almost always present to some degree.

Schizophrenia has a similar prevalence rate as bipolar disorder, with an estimated annual prevalence rate of about 1.3% of the population (Robins & Reiger, 1991), translating into about 2.2 million people in the United States. Most people develop schizophrenia before the age of 40 and the typical onset is between adolescence to early adulthood (McEvoy, Scheifler, & Frances, 1999). Schizophrenia is generally a chronic illness where some degree of impairment is present at all times. Most individuals experience relapses where symptoms worsen or new symptoms appear and relapse often leads to hospitalization until the symptoms are once again stabilized. Like bipolar disorder, schizophrenia is thought to be caused by a combination of genetic and environmental factors.

Comorbid Conditions in Schizophrenia

As in bipolar disorder, substance abuse is prevalent among individuals with schizophrenia. It is estimated that 80-90% of individuals with schizophrenia smoke (APA, 2000). The prevalence rates of alcohol and marijuana abuse in schizophrenia are estimated at 37% and 23%, respectively (Cuffel, Heithoff, & Lawson, 1993). Research indicates that sensory abnormalities associated with schizophrenia are temporarily corrected with nicotine; therefore, smoking may be a form of "self-medication" (McEvoy & Allen, 2002). Self-medication may also play a role in the use of alcohol and other drugs (Green, Salomon, Brenner, & Rawlins, 2002), although there are many other contributing factors to consider.

Anxiety and depression are also common comorbid conditions in schizophrenia. Cosoff

and Hafner (1998) report a 43-45% prevalence rate of anxiety disorders in people with schizophrenia. Estimates of depression among individuals with schizophrenia range from 7-65% (Bartels & Drake, 1988; Delisis (1990), with a modal rate of 25% (Siris, 2000). Both anxiety and depression are often overlooked by clinicians, but are clearly important to address when considering increased functional impairment, risk of suicide, and long term care planning. People with schizophrenia commit suicide at a much higher rate than the general population with estimates of suicide attempts in people with schizophrenia ranging from18-60% and suicide completion rates ranging from 9-13% (Roy, 1986; Meltzer & Okayli, 1995).

Treatment for Schizophrenia

Treatment for schizophrenia involves a broad range of interventions, including medications, psychoeducation, and therapy. The psychotherapeutic interventions for schizophrenia are essentially the same as for bipolar disorder; therefore, the remainder of this section will focus on medications. Antipsychotics are the mainstay of pharmacotherapy and are divided into two categories: conventional and atypical. The conventional antipsychotics are older agents that primarily target dopamine receptors. Some examples of conventional antipsychotics are haloperidol, chlorpromazine, and stelazine. While the conventionals are effective at treating positive symptoms (i.e., delusions and hallucinations), they are less effective at treating other symptom domains such as negative and cognitive symptoms. Serious side effects such as such as tardive dyskinesia (TD) (abnormal, involuntary movements commonly of the mouth, face, or extremities) and extrapyramidal symptoms (EPS) (restlessness, tremors, muscle contractions and rigidity) can occur with conventional agents. Atypical antipsychotics are recommended over conventional agents because of their increased efficacy and tolerability (McEvoy, et al., 1999). The first atypical agent, clozapine, came into use in the United States in 1990. Since then, other atypical antipsychotics have been developed, including olanzapine, risperidone, quetiapine, and ziprasidone. In contrast to the conventional agents, atypicals target multiple neurotransmitters, including serotonin, rather than focusing only on dopamine. This diversity is thought to improve the atypicals efficacy and reduce likelihood of developing side effects such as tardive dyskinesia. Many atypical agents have shown equal efficacy in positive symptoms as conventional agents and superior efficacy in the treatment of negative symptoms and cognitive symptoms (McEvoy, et al., 1999). Additionally, there is evidence that the atypicals are effective in treating anxiety and depression (Meltzer & Okayli, 1995; Tollefson, Sanger, Beasley, & Tran, 1998), and may even reduce substance abuse rates (Zimmet, Strous, Burgess, Kohnstamn, & Green, 2000; Littrell, Petty, Hilligoss, Peabody, & Johnson, 2001). As with all medications, the atypicals do have side effects which commonly include drowsiness, dry mouth, constipation, dizziness, orthostatic hypotension, sedation, nausea, and weight gain.

The use of multiple medications or polypharmacy is becoming increasingly common in psychiatric practice, and schizophrenia is no exception (Stahl, 1999). In addition to antipsychotics, commonly prescribed medications include mood stabilizers, anticonvulsants, antidepressants, and anti-anxiety drugs. Additionally, anticholinergics are often prescribed for extrapyramidal side effects. Refer to Table 1 for a list of commonly prescribed agents and their estimated costs and Table 2 for common psychotherapeutic interventions and costs for clients with SPMI.

It is important to note that treatment noncompliance is very common in people with schizophrenia. It is estimated that 75% of patients with schizophrenia stop taking their medication within two years of leaving a hospital or treatment program (Weiden, Rapkin, &

Mott, 1994). Discontinuing medications increases the likelihood of relapse and rehospitalization, which can lead to progressive deterioration in functioning.

Costs of Schizophrenia

Due to the chronicity of the illness, schizophrenia is costly both in terms of economics and quality of life. It is estimated that schizophrenia costs the United States about $32.5 billion dollars per year (NIMH, 2003). As with bipolar disorder, the most costly intervention in treating schizophrenia is hospitalization for relapse (Thieda, Beard, Richter, & Kane, 2003). Predictors of relapse in people with SPMI include race, previous hospitalizations, and type of aftercare residence or program (Yamada & Korman, 2000). Reducing the economic burden of schizophrenia is incumbent on decreasing hospitalization rates and increasing the accessibility to atypical antipsychotics which could improve outcomes due to increased efficacy and tolerability. Accordingly, evidence is mounting that treating individuals with schizophrenia with atypical antipsychotics, despite their higher acquisition costs, could help reduce the overall costs of schizophrenia (Davies, Langley, Keks, Catts, Lambert, & Schweitzer, 1998; Finley, Sommer, Corbitt, Brunson, & Lum, 1998; Palmer, Brunner, Ruiz-Flores, Paez-Agraz, & Revicki, 1998; Hamilton, Revicki, Edgell, Genduso, & Tollefson, 1999).

Case Study

Jane is a 26-year-old Caucasian female who has been diagnosed with bipolar disorder for about two years. She has had depressive episodes throughout her late teens and early 20s and her first manic episode appeared at age 24. During this manic episode she was fired from her hairstylist position because she instigated a verbal altercation with the owner of the salon. Her condition deteriorated rapidly, resulting in hospitalization and a diagnosis of bipolar disorder. She required hospitalization for two weeks during this manic episode and then was treated as an outpatient for about six months, at which time she discontinued her medications and dropped out of the program. Within four weeks, Jane had another manic episode with psychotic features. She experienced visual and auditory hallucinations and had paranoid delusions. A family member went to her apartment after there was no contact with her for several weeks. The apartment was filthy, and Jane had covered up all of the mirrors in the house with sheets. She had not bathed in several days. She was hospitalized again for another two weeks.

After discharge, Jane was enrolled in another program with more intensive treatment (daily). Her family participated in therapy with her. She made social contacts with other people enrolled in the program and began to create a support network. A different medication regimen was started, where Jane did not have to have blood draws, which contributed to her previous non-compliance. She sometimes had difficulty remembering her medications, so a system was set up where she had a watch alarm that would signal the times to take her medications. Her medication box was set up on a weekly basis by a nurse at her treatment center.

After staying in treatment for about 10 months, Jane wanted to return to work part-time. Her previous vocation was a licensed hairstylist, which she enjoyed, but had often found to be stressful. She wanted to meet with the treatment center's rehabilitation counselor to discuss her future vocational plans. Jane's parents are elderly and concerned about her ability to provide for herself financially after they are deceased and they wanted to investigate the costs of Jane's treatment over the long-term in order to create a trust for her. See Table 3 for an example life care plan for Jane.

Table 3. Sample Basic LIFE CARE PLAN for Jane

LIFE CARE PLAN			
Medical/Therapy Needs			
Recommendation	**Dates**	**Frequency**	**Expected Cost**
Psychiatrist for medication management. Nurse takes vital signs and sets up medication box.	2003 to life	Minimum 1 X per month (may be 1 X per week during acute illness/ relapse).	$100 each visit (average time 20 minutes). Cost of nurse is included.
Individual counseling	2003 to life	1 hour/week during acute illness or crisis (1 yr), 1-2 hours/month when stable.	$100 each visit. Expect 48 therapeutic weeks per year.
Group counseling	2003 to life	Same as above.	$40 each session
Family counseling	2003 to life	1 X per week until stabilized (est. 6 months) then expect 4 X year for 10 years (dependant on severity of symptoms and family's role in treatment).	$125-150 each session
Psychoeducation	2003 to stabilization (est. 1 year) then as needed	2 X per month up to stabilization, then as needed.	$30 each session for 1 year then unknown
Support Group	2003 to life	1 X per month.	$0-30 per session
Medication/Lab			
Recommendation	**Purpose**	**Dosage/duration**	**Expected Cost**
Anticonvulsant/ Mood stabilizer	Treat bipolar symptoms, relapse prevention.	2003 to life	$50-200 each month, dependent on which agent is used. $100-150/lab (not all agents require lab monitoring).
Atypical Antipsychotic	Treat psychotic symptoms, mood instability.	2003 to life	$200-500 each month, dependent on agent and dose.

Benzodiazepine	Help control acute mania, anxiety.	2003 to life, as needed	$90 per month (est.)
Vocational Related			
Recommendation	**Dates**	**Frequency**	**Expected Cost**
Vocational Evaluation	2003	1 X	$750
Job Analysis (8 hr. @ $75/hr.)	2004	1 X	$600
Books, tuition, fees, supplies for 1 yr. training (estimate)	2004	1 X only	$1,500 (est.)
Job development	2005	25 hours @ $75/hr.	$1,875 (est.)
Supported Employment/Job coaching assistance	2005	100 hours @ $35 per hour.	$3,500
Non-Medical			
Recommendation	**Dates**	**Frequency**	**Expected Cost**
Guardian/financial assistance for contracts and bills	2003 to life	2 hours/month (average)	$100/hour (parents currently perform this function)
Medication Organizer	2003 to life	Replace every 5 yrs (loss or damage)	$5.00
Housekeeping Services (to work with client)	2003 to life	2 X per month	$50-100 each visit (dependent on size of living space and duties)

Potential Complications

- Poor compliance due to side effects of medications or "other" factors leading to relapses and hospitalizations.
- Adverse reactions to medications (e.g., drowsiness, dry mouth, constipation, dizziness, orthostatic hypotension, sedation, nausea, and weight gain).
- Job placement difficulties which require more than one occasion of support.
- Loss of family support (e.g., death of one or both parents) resulting in relapse requiring more psychological support than planned.
- Movement disorders (such as tardive dyskinesia – TD - or extrapyramidal symptoms – EPS) which can be permanent and debilitating.
- Dental complications from long-term use of medications.

Life Care Planning and SPMI

It is clear that there are many issues to consider when developing a life care plan for individuals with SPMI. Factors such as diagnosis, age of onset, response to treatment, and comorbid conditions contribute to overall outcomes. Table 4 provides a checklist of pertinent issues for the life care planner to consider when developing the plan. Treatment of SPMI is constantly evolving as new research provides a greater understanding of the processes involved in mental illness and the development of new medications continues to brighten the long-term outlook for people with SPMI. Currently, individuals with SPMI and their families have little structured information in regards to planning for the lifetime costs associated with severe mental illness. Traditionally, families have turned to estate planners for such services, however, it is unclear if such approaches are adequate, as their usefulness has not been systematically studied. While life care planning traditionally has not been utilized in the SPMI population, it is clear that these individuals would benefit from such a resource.

Table 4. Life Care Plan Checklist for Severe and Persistent Mental Illness

- ✓ What is the diagnosis, predominant symptoms, and expected course?
- ✓ What treatment modality will be required? Is hospitalization or partial hospitalization needed? Is residential or day treatment recommended?
- ✓ What medications will be used? What dose and duration is expected? Is lab work required? If yes, then for what duration? How often will psychiatrist be seen? Is individual compliant with medications?
- ✓ What psychotherapeutic interventions will be required? Is family accessible and present in individual's life? Is a support network established?
- ✓ Is substance abuse present? If yes, what interventions will be required?
- ✓ Are other comorbid psychiatric diagnoses present? If yes, to what extent is functioning impaired? Are specific interventions present that target comorbid conditions?
- ✓ Are there any comorbid health concerns (i.e., obesity, diabetes, hypertension)? What interventions will be required? How is care coordinated?
- ✓ What is the individual's work history? Has vocational potential been assessed? Has supported employment been considered or implemented?

Note: Reimbursement for services is typically provided by a combination of resources including Medicaid/Medicare, health insurance policies, and private pay. Many pharmaceutical companies have Patient Assistance programs where medications are provided free or for a nominal charge for eligible, low-income individuals who demonstrate a need.

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