EMOTIONAL STAGES: CONSUMERS AND FAMILY MEMBERS RECOVERING FROM THE TRAUMA OF MENTAL ILLNESS

Contents

1. INTRODUCTION
2. CONCEPTUAL MODELS OF LOSS
3. THE JOURNEY OF HOPE PROGRAM
4. THE BRIDGES PROGRAM
5. EMOTIONAL STAGES OF RECOVERY
6. EMOTIONAL STAGES OF RESPONSE
7. THE VALUE OF CONCEPTUAL MODELS IN SELF-HELP
8. USE OF THE "EMOTIONAL STAGES OF RECOVERY" IN THE BRIDGES PROGRAM
9. CONCLUSION
10. REFERENCES

FOR INFORMATION CONTACT DR. ELIZABETH A. BAXTER AT TENNESSEE BEHAVIORAL HEALTH, INC., 209 10TH AVENUE SOUTH, SUITE 547, NASHVILLE, TN 37203, (615) 259-6000.

People with severe mental illness experience a profound degree of loss. Recovery from severe mental illness involves grieving this loss and adapting one's social role to a restructured sense of self. In this article the authors describe several conceptual models of loss and introduce two additional models specific to the experience of people with mental illness and their family members. The BRIDGES program and the Journey of Hope are peer-taught programs that offer education and support to people with severe mental illness and their families. Within these programs, the models function to validate participants' experience of loss as normal and to provide a structure for a new sense of self. This helps people with severe mental illness and their families to move from isolation and loneliness to empowerment and reconnection with an ordinary life.

INTRODUCTION

Humankind has sought for ways to make sense of bad things that happen to people. People with mental illness have suffered devastating losses for centuries. These losses were often thought to be permanent because there was no hope for cure. Recently, people with mental illness have regained hope by distinguishing "cure" of mental illness from "recovery" of social function. This
The article proposes a conceptual framework of the process of recovery used in the BRIDGES program for mental health care consumers and compares that process to a corresponding model of family adaptation used in the Journey of Hope. These suggested models potentially can help participants make sense of what is happening to them and progress toward a more satisfying life course.

CONCEPTUAL MODELS OF LOSS

Every person will experience loss and traumatic circumstances at some point in life. Certain experiences seem to jolt a person from an anticipated life course. The threat of death or serious illness, one's own or that of a loved one, seems to be a common focus for the experience of loss. During the course of recovery from loss, a person often searches for ways to conceptualize it. Questions may arise such as, "Why me?" and "How do I cope with this and get back on my feet?" and then eventually, "How am I changed by this experience?" Models conceptualizing loss can be used to make sense of these experiences and to help oneself or others resume meaningful life roles.

Erich Lindemann (1944), in his study of the survivors of the Chicago Coconut Grove Fire, defined the process of grief as a normative, rather than pathological, response to trauma. The first stage of this process is to forget or deny that the trauma occurred.

Elisabeth Kubler-Ross has dealt with this topic in her 1969 work, On Death and Dying. Dr. Kubler-Ross described the following stages of attitudes toward death and dying: denial, anger, bargaining, depression, and acceptance. She stated that hope of a cure is present through all of these stages. Although she focuses exclusively on the process of death, her work can be extrapolated to other types of loss. Physical illness is a fundamental form of loss. Mental illness is a more nebulous and stigmatized form of loss and is thus harder for many to conceptualize.

Mental illness is traumatic and involves losses from which people need to recover. Judith Herman (1992) suggests three tasks in progressing from such an initial trauma to recovery. These tasks include the establishment of safety, remembrance and mourning, then reconnection with ordinary life. She states, "Helplessness and isolation are the core experiences of trauma. Empowerment and reconnection are the core experiences of recovery" (p. 197).

Patricia Deegan (1988) experienced mental illness personally before she had the opportunity to study it professionally. By integrating her experiences as a consumer and a provider of mental health care, she gives us a rich understanding of the experience of mental illness. She disputes the implied advice commonly given to people who are diagnosed with mental illness that, since their disease had no cure, they should settle for a semblance of a life. She groups the stages of recovery from mental illness into denial, despair, and anguish, and finally the cornerstones of recovery: hope, willingness, and responsible action.

Larry Davidson and John Strauss (1992) revived the classic construct of the sense of self as crucial to recovery from mental illness. After listening to many people who suffer from mental illness, they assert that rebuilding an "enhanced sense of self" protects people from being
overwhelmed by the illness and gives them a solid basis for progressing toward recovery. Dr. Strauss suggests three phases of recovery: stabilization, reassessment, and integration.

Based on longitudinal studies that span decades, researchers such as John Strauss, Joseph Zubin, and Courtenay Harding (1992) assert that recovery from schizophrenia and related disorders is more common than formerly thought. They state that as the aging process begins to dampen symptoms, taking responsibility for oneself in the person-illness-environment interaction is a key to the recovery process.

In all of these models the concept of recovery is central. William Anthony (1993) has refined the concept of recovery from mental illness and distinguished it from cure. He defines recovery as "the development of new meaning and purpose in one's life as one grows beyond the catastrophe of mental illness" (p. 19). Anthony states that recovery from the effects of the illness on one's life circumstances (e.g., poverty and isolation) tends to be more challenging than recovering from the illness itself. He further states that, "recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals and skill and/or roles" (p. 19).

While recovery is a goal for people diagnosed with mental illness, family members and supporters go through a different process. Agnes Hatfield (1987) suggests that family members go through the phases of stress, coping, and adaptation. The goal of the family is to adapt to the ongoing burden of caring: for someone with a mental illness. A sense of mastery over the situation is a key factor in developing adaptations that allow the family to regain a sense of balance (McCubbin et al., 1980). Education and skill building are building blocks toward this crucial sense of mastery, dispelling fear of the unknown and providing tools by which to manage difficult events and interactions. Social support is another major factor that lightens the burden of family and friends (Potasznik & Nelson, 1984).

In the Journey of Hope, families learn that their feelings are "normative reactions" (Burland, 1995), given the trauma they are exposed to. Families learn that their reactions are not pathological, but that there is a pattern of progression from the initial shock of having a family member with mental illness, to the final acceptance of their loved one's loss and the resumption of adaptive family relationships. Family members need to be validated and assisted with achieving emotional resolution rather than being blamed for pathological responses.

These respective conceptual models undergird the BRIDGES consumer program and Journey of Hope family program. By building on these established foundations, both programs provide guidance and support valued by consumers and family members alike.

**THE JOURNEY OF HOPE PROGRAM**

BRIDGES was modeled after the Journey of Hope family education and support process. Both BRIDGES and the Journey of Hope are unique in that all teachers are peers rather than professionals. The Journey of Hope family education program consists of a 12-week course on thought disorders, mood disorders, medication, rehabilitation, empathy for loved ones, communication and problem-solving skills, self-care for family members, and effective advocacy. The goal of the course is to achieve empathy for loved ones and to help family
members resolve the emotional trauma of having persons with mental illness in the family. The course is taught by family members who volunteer their time to participate in training and to teach the course. At the completion of the course, members are invited to an ongoing support group facilitated by trained family members. The Journey of Hope is also disseminated state by state sponsored by the Alliance for the Mentally Ill. As with BRIDGES, no tuition is charged to participants.

**THE BRIDGES PROGRAM**

"BRIDGES: A Journey of Hope" is a program that offers a peer-taught course on mental illness and recovery, and ongoing support groups that are facilitated by people diagnosed with mental illness. The program was developed by the Tennessee Alliance for the Mentally Ill and the Tennessee Mental Health Consumers' Association in response to countless requests for solid information about mental illness, mental health services, individual self-help skills, and group facilitation training. The acronym, BRIDGES, stands for Building Recovery of Individual Dreams and Goals through Education and Support. As its full name implies, BRIDGES is a companion to the Journey of Hope family education and support program sponsored by the Louisiana Alliance for the Mentally Ill. The effort, in developing companion programs, is to offer information and supportive environments that answer the distinct needs of consumers and family members, and to establish a common knowledge base and set of skills to ease interactions between consumers and their loved ones.

The 14-week BRIDGES course was written by a team consisting mostly of people diagnosed with mental illness. The course content was developed through focus groups conducted with 100 consumers in ten communities across Tennessee. This course covers topics such as the concept of recovery from mental illness, clear and useable descriptions of thought disorders, mood disorders, anxiety disorders, personality disorders, building effective support systems, mental health treatment including medications and community support services, communication and problem-solving skills, spiritual concerns, and effective methods for advocacy. There is an emphasis on building trust and sharing personal experiences of mental illness with a view toward developing a group where members support each other on an ongoing basis. As one member expressed, "This course addresses the isolation that our illness forces upon us with a level of social bonding that I never expected to find, and do not find in any other area of my life." At the close of the course, members are invited to an ongoing support group using the knowledge and skills from the BRIDGES course.

BRIDGES is disseminated state by state through the joint sponsorship of a state consumer group and the state Alliance for the Mentally Ill Affiliate. No tuition is paid by participants, the course being supported through funds obtained by the sponsoring organizations. BRIDGES teachers are paid both for the intensive training session and the actual teaching of the course. In our current fiscally conservative environment, this is costeffective psychoeducation that empowers consumers to learn and then teach others. For many BRIDGES teachers, this is the first experience of meaningful work since being diagnosed with a major mental illness.

**EMOTIONAL STAGES OF RECOVERY**
"The Emotional Stages of Recovery" (Diehl, 1995) is a conceptual model developed as part of the BRIDGES program and is offered to help participants explore their own recovery process. This model was constructed using a two-step method. First, a questionnaire was developed based on constructs in the recovery literature. Then interviews were conducted by consumers employed by BRIDGES. A convenience sample of 40 consumers was interviewed face-to-face across Tennessee. Using content analysis, responses were condensed into a suggested model involving three psychological "events," each followed by a stage (see Table 1). "The Emotional Stages of Recovery" uses the words of consumers to suggest similarities in their experience.

The first proposed mental event is a crisis caused by mental illness such as psychosis, a suicide attempt, mania, panic, or some other trauma. It is a time of confusion. Actions taken during this period may result in dire consequences. The person may emerge from the crisis feeling exhausted and needing to recuperate. Denial and negative emotions toward self and others may predominate. The person may be reduced to the level of basic needs for sleep, food, and shelter. The second mental event may come any time from few days to a few years after the crisis. During this event the person may make a decision to get going again. This decision may be followed by the stage of rebuilding the ability to care for oneself and to assume normal life roles. During this stage, the person could expect setbacks and success. By persevering through the seesaw emotions of the rebuilding stage, the person may come to a more integrated sense of self. The third mental event proposed is an awakening to one's restructured personhood. This awakening may be followed by the stage of recovery, when the person may reconnect with the natural rhythm of life in healthy interdependence.

EMOTIONAL STAGES OF RESPONSE

In the BRIDGES program, recovery is viewed as a biological and psychological process. BRIDGES teaches that biology and environment can be influenced by the person who is recovering. In the Journey of Hope, emotional resolution by family members is seen as a psychological process which can also be influenced by participants. Table 2 portrays the "Stages of Emotional Response" (Burland, 1990) as used in the Journey of Hope.

The "Emotional Stages of Response" is a conceptual model of family members' emotional resolution following the trauma of discovering that a family member has a severe mental illness. There may be an initial sense of taking one's head out of the sand as the shock hits that something is seriously wrong with a loved one. There may be a tendency to deny the severity of the problem with reasoning like, "If he just tries harder, things will go better," or "It is just teenage hormones." The family at this point may need support, crisis intervention, and a prognosis. By the second stage, the family may be learning to cope and needs to communicate with others who have been through the experience. As the seriousness of the illness becomes clear to family members, the grief process may deepen. Families may need to vent, and they may need education about the illness and skills for self-care. As the family comes into an acceptance of the illness, they may move into advocacy. The family needs responsiveness from the mental health system to provide some ongoing, intensive supports for the person with mental illness. There is a need to restore the balance in family life by responding to the needs of each family member.
As consumers and family members progress through their respective recovery process and resolution of emotional trauma, there may be numerous opportunities for lack of synchronicity. Neither process is seen as linear, as participants are often working back and forth across the model. For the sake of simplicity, however, the two suggested processes will be compared below as if they flowed in a step-by-step manner.

The consumer who is in crisis is often unable to reach out and ask for help, but is desperately needing it. Family members may need to use denial, believing that the crisis is not actually occurring, or that it is not serious. Family members and consumers may remain in denial for months, which makes it very difficult to move toward early intervention. By the time consumers and their families present at the hospital, they are often in deep crisis. Family members may recognize sooner than the consumer that something is wrong and that help is needed. This is commonly a source of conflict between consumers and their loved ones.

As the crisis subsides, the consumer is physiologically and psychologically recuperating. Common feelings may include denial, despair, confusion, and anger. There is a desperate need to sleep a lot, and to be fed, sheltered, and allowed to ruminate.

Family members, meanwhile, may be moving into their second stage of learning to cope. They may not realize the depth and seriousness of the consumer's illness, that something is medically wrong. They may think that the consumers' effort and willpower could bring him or her back to normal if the consumer only tried hard enough. At this point family members may be exhausted and may want it all to go back to the way it was. They may feel that a magic key exists, which can restore the consumer quickly and completely to a previous state of health. This could result in family members feeling guilty themselves and angry at others for not having the answers or "doing the right thing." Family members may feel anger toward the consumer for "just sitting there" and not trying to get better. This anger may emerge just at the time when the consumer needs support for rest and introspection.

As the consumer starts to make the decision to "get going" and begins to rebuild, family members may recognize the seriousness of their loved one's illness and may begin to grieve the loss of the consumer's ability to function. Family members may be adjusting their expectations and withdrawing from the consumer in an effort to create a less stressful environment and also to regain balance in the rest of the family. This could come at a time when the consumer needs others to listen with acceptance and to support efforts to rebuild. During this time the consumer needs encouragement to try, empathy during setbacks, and applause for successes.

As the consumer awakens to the restructured self and begins to hope, there is a need to engage in the natural rhythm of ordinary life. This includes a need to give to others, including family members. Family members, however, may have come to an understanding and acceptance of the losses associated with the illness. Family members may advocate for services that protect the consumer in the event of future crises. Consumers may see this as patronizing and discounting of their achievements and future potential. In general, the consumer movement advocates for self-direction while the family movement advocates for protection.
Family members often state that the goal for their loved one is wellness, but they may be much more aware of vulnerability to illness than the consumer. Family members, in figuring out what posture to take, may ask, "What is my proper role in guarding them against the vulnerability created by their illness?" They may wrestle with the dilemma of how much protection is necessary and how much independence is realistic.

While the worst-case scenario portrayed above may exist between many people with serious mental illness and their loved ones, there is potential for the process to go more smoothly. By acknowledging the points of stress and voicing what is needed in those times, the family may pull together with the consumer in emotional understanding, mutual forgiveness, and support. This would strengthen the natural support system of family, friends, and others. The result of this process can be empowerment, which leads to social action. Advocacy can be an essential part of reparation and healing.

THE VALUE OF CONCEPTUAL MODELS IN SELF-HELP

These conceptual models for consumers and those who care about them are important for several reasons. First, they provide maps that consumers and their loved ones can use to navigate stormy times. The respective maps remind consumers and family members that there can be times of peace and stability. This helps consumers and family members realize that the experience of mental illness and its effects is not an uncharted wilderness, but a domain that has been explored by others who can serve as guides.

Comparing models of recovery for consumers with models of adaptation for family members normalizes the tempestuous times in the family/consumer relationship. This guides the process of resolving conflicts in a way that can lead both parties to a more integrated and hopeful sense of the future.

Finally, conceptual models are important to guide consumers and family members in treatment decisions. The right treatments at the right point in the process can foster recovery in consumers and adaptation in family members. Treatments at the wrong time can injure consumers and family members. As years of heartbreak among consumers and family members have demonstrated. Consumers and family members may benefit from combining knowledge of the recovery and adaptation processes. Using this knowledge with information on best practices in mental health care may help consumers and family members make judicious use of professional services to augment their natural support system, rather than to displace it. In BRIDGES and the Journey of Hope, these dynamics have begun. Further research is necessary to determine dimensions of the trends and whether they will continue.

USE OF THE "EMOTIONAL STAGES OF RECOVERY" IN THE BRIDGES PROGRAM

Finding others who are going through a similar process of mental illness helps to reduce the sense of isolation experienced by consumers and their loved ones. Finding peers experienced with mental illness and working with them heals the wounds created by isolation. Identifying with peers and reconnecting with the world at large is the final stage of healing discussed by Herman (1992).
When BRIDGES Emotional Stages were used in BRIDGES pilot study classes, consumers could easily identify their placement along the continuum of emotions and events. They felt validated; it was "OK" for them to need rest if they saw themselves in the first stage. They were not being "lazy" as others may have told them before. Most importantly; their pain and problems could be reframed as stages of growth, with hope that they would ultimately reach happier and more peaceful times. Not only did this hopefulness give consumers the strength to keep going, but family members and providers could be reassured that, given time and attention, consumers could and would work through their problems.

This positive reframing is a central contribution of the "Emotional Stages of Recovery." In addition, the people who participated in BRIDGES were able to see similarities among themselves, and thus feel closer to people they had once felt: very different and distant from. They were able to set aside personal differences and work more closely to solve problems, creating an informed support system.

Consumers found the words to explain their experience to family members. Family members could finally understand the pain their loved ones felt. They also had a better idea of the kind of support their loved ones were asking for.

BRIDGES participants have taken the "Emotional Stages of Recovery" to providers to help explain their internal experience, Providers have reacted positively to this model as a therapeutic tool for their clients.

CONCLUSION

In the BRIDGES program, people with mental illness have used the "Emotional Stages of Recovery" to make sense of their suffering and losses, and to progress to an integrated sense of self. Their responses have been validated as normal and part of a shared experience with other consumers. This helps them move from isolation and helplessness to empowerment and reconnection with people they care about. Although individuals may still have symptoms of their mental illness, they can and do recover meaningful social functions. In the Journey of Hope, the "Emotional Stages of Response" similarly validate family members' experiences and bring them into contact with other grieving families. The twin approaches of BRIDGES and the Journey of Hope bring family members and consumers into a common language and recognition of their respective trauma. This lays the foundation for the ultimate resolution of trauma and facilitates family reunification.

Table 1--Emotional Stages of Recovery

<table>
<thead>
<tr>
<th>EVENT</th>
<th>CRISIS:</th>
<th>PSYCHOSIS, SUICIDE ATTEMPT, MANIA, PANIC ATTACK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1)</td>
<td>Recuperation:</td>
<td>A stage of dependence</td>
</tr>
<tr>
<td></td>
<td>Emotions:</td>
<td>Denial, confusion, despair, anger</td>
</tr>
<tr>
<td></td>
<td>Needs:</td>
<td>Safe place, food, lots of sleep</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A caregiver</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medications (probably)</td>
</tr>
<tr>
<td>EVENT 2)</td>
<td>DECISION:</td>
<td>&quot;TIME TO GET GOING.&quot;</td>
</tr>
<tr>
<td>Stage 2)</td>
<td>Rebuilding:</td>
<td>Rebuilding independence</td>
</tr>
</tbody>
</table>
Emotions: Grief, self-doubt, hope, anxiety, frustration, pride
Needs: To be heard and accepted
Learning: about mental illness, people skills, work skills
Money, food, clothes, good place to live

EVENT 3) AWAKENING: "I AM SOMEBODY. I LOVE A DREAM."
Stage 3) Recovery/Discovery: Building healthy interdependence
Emotions: Acceptance of self and others, confidence, anger at injustice, helpfulness to others
Needs: A dream to strive for
People who appreciate me
Intimacy: someone to love
Meaningful work
Fun and physical activity
To advocate for self and others

Table 2--Stages of Emotional Response Among Family Members

I. HEADS OUT OF THE SAND

Crisis/chaos/shock
Denial: "normalizing"
Hoping against hope
Needs: Support - Comfort - Empathy for confusion - Help finding resources Crisis intervention - Prognosis - Empathy for pain

- AMI

II. LEARNING TO COPE

Anger/guilt/resentment
Recognition
Grief

Needs: Vent feelings - Keep hope - Education - Self-care Networking - Skill training - Letting go - Co-op from system

III. MOVING INTO ADVOCACY

Understanding
Acceptance
Advocacy/action

NEEDS: Activism - Restoring balance in life - Responsiveness from System

REFERENCES


~~~~~~~~
BY ELIZABETH A. BAXTER. & SITA DIEHL

ELIZABETH A. BAXTER, MD, IS A CONSUMER ADVOCATE, TENNESSEE BEHAVIORAL HEALTH, INC.

SITA DIEHL., MA, MSS, IS AN EVALUATOR FOR THE TENNESSEE ALLIANCE FOR THE MENTALLY ILL, NASHVILLE, TENNESSEE.