

Recovery narratives: 'see how far I've come'

Narrativas de recuperação: 'veja onde cheguei'

Richard Weingarten¹, Maria E. Restrepo-Toro²

Abstract

As the paradigm shift towards a recovery-oriented mental health system becomes more prominent, individuals with lived experience of mental illness will continue to write and speak their narratives of mental illness and recovery. This article discusses the social reality of people with mental illness: how they are stigmatized by the media and how competing narratives within the mental health system afflict people with this disability. It also discusses the empowering process of constructing a narrative that enables the narrator/speaker to find meaning in her/his experience while putting a realistic 'face' on mental illness and recovery for the general public. It further describes how telling a narrative to diverse audiences, including a college class of 'people in recovery' enhances the author's personal recovery by giving his life new meaning and purpose.

Keywords: process of recovery; narrative; strengths; self-stigma; valued social role.

Resumo

Na medida em que a mudança de paradigma para um sistema de saúde mental orientado à recuperação se torna mais proeminente, indivíduos com experiências de vivência de doença mental continuarão a escrever e contar suas histórias de doença mental e recuperação. Este artigo discute a realidade social das pessoas com doenças mentais: como elas são estigmatizadas pela imprensa e como outras linhas discursivas dentro do sistema de saúde mental as afetam. O artigo também discute o processo de capacitação que a construção da narrativa oferece ao narrador/palestrante, possibilitando-o a encontrar um significado para sua experiência ao mesmo tempo em que fornece uma 'face' realista à doença mental e recuperação para o público em geral. O artigo também descreve como o processo de contar a narrativa a audiências variadas, inclusive uma turma de faculdade de 'pessoas em recuperação', acentua a recuperação pessoal do autor na medida em que dá à sua vida um novo sentido e propósito.

Palavras-chave: processo de recuperação; narrativa; vantagens; autoestigma; papel social valorizado.

Study carried out at Yale University School of Medicine and Boston University – Yale, USA.

¹Master of Arts, Certified Psychiatric Rehabilitation Practitioner; President of Forward Spiral Associates; Director of Consumer Initiatives and Education for Southwestern Connecticut and Assistant Clinical Professor, Department of Psychiatry, Yale University School of Medicine – Yale, USA.

²Master of Sciences, Certified Psychiatric Rehabilitation Practitioner; Senior Training Associate, Latino Initiatives, Boston University, Center for Psychiatric Rehabilitation – Boston, USA.

Mailing address: Richard Weingarten – 57 Harbour Close, New Haven, CT 06519, USA – E-mail: r.weingarten@comcast.net

Financial support: none.

Conflict of interest: nothing to declare.

■ INTRODUCTION

I know, personally, how empowering narratives can be¹. As a person with a mental illness, writing out and speaking publicly, my narrative provided me the opportunity of reflecting on what had happened to me and to recount the gains I made in understanding and managing my illness. I spoke of meaningful activities and relationships that propelled my life forward in recovery. I told of my challenges and struggles, but also of my victories and accomplishments. I had worked hard on myself and I was proud of how far I had come.

In a recent speech at a mental health conference in Utrecht, Holland, I talked about my long journey of overcoming self-stigma¹. I told the audience that after I became ill I internalized the stereotypes people had of subjects with mental illness, e.g. we were dangerous, unpredictable and incompetent, and I withdrew from social contact. I felt “less than” (inferior to) my friends and former classmates. They were moving on with their lives while I was standing still. Fortunately, a good friend counseled me to stop comparing myself to my former classmates. At that point I decided to play the cards I was dealt.

I told the audience how I was stigmatized and was rejected by a girlfriend who said I had no future and that she never wanted to see me again. I related how a prospective newspaper employer terminated a job interview when I revealed that I took medication for a mental illness. The newspaper publisher said that I would not be able to withstand deadline pressure. Gradually, I learned whom to trust or not trust with this potentially damning information, and when it was okay to reveal this part of myself and when it was not.

With the help of a skillful therapist, I identified my writing and speaking abilities as strengths that could be used to pull my life forward. I joined a self-help group that had a grant to write a handbook for patients being discharged from a mental hospital in Cleveland, Ohio. When the booklet was finished, I sent a copy to my former therapist, who praised it for looking very professional and wondered whether could I become an ‘information giver’ for other users of mental health services and the general public.

I took the therapist’s suggestion and ran with it. I started writing about my illness and recovery and speaking out about it in public. This ‘valued social role’ gave my life new meaning and purpose. I also started to read books and articles about stigma and self-stigma. Among these was Erving Goffman’s classic study: “Stigma: notes on the management of spoiled identity”². From another book, “The Body Silent”, I learned which parts of my ‘damaged’ self needed work³.

I was battling depression at the time and joined a mood disorders support group. Later on, as my depression lifted, I became a participating member of the group and eventually took a leadership role, facilitating the group meetings. Also, I joined a spiritual community where I made new friends. At the church’s fellowship hour, I re-learned social skills that I had lost during my reclusive years.

With these modest gains, I decided to test myself outside the mental health system. I began teaching Portuguese and Brazilian culture at John Carroll University in Cleveland. Facing early morning classes of 40 or more students, I was often depressed. However, I found I could push aside the depressive feelings and deliver my lectures. I also stopped being such a perfectionist and thus enjoyed teaching my students even more. This experience gave me the confidence to engage in a national job search in the mental health field. My long-term goals were to work full-time and become financially independent. I yearned for the active life that I had in Brazil before becoming ill. After two years trying to find a position, I landed a job at a large mental health center in New Haven, Connecticut, as the Director of Peer Support.

In New Haven, working full-time, I was no longer troubled by self-stigma and began testifying on behalf of other users and their families at the state legislature. Later, I brought a national video program to Connecticut that afforded users an opportunity to tell their recovery stories to a wide range of audiences throughout the state. The first year, my team and I presented more than 100 video programs. In 2003, I was given a “Stigma Buster Award” for this work.

Now as I am retired from state service, I give workshops on stigma, self-stigma, recovery and peer support in the U.S. and Canada, but also abroad in the Netherlands, Brazil, and Israel. I use my journey of overcoming self-stigma and reducing stigma in society generally as an example that users and families can also conquer stigma and self-stigma.

Telling my recovery narrative to different audiences gave me a valued social role, which was important to my recovery and personally fulfilling¹. Through my narrative, people gained accurate information about mental illness and recovery, thus challenging the prevalent stigma and misconceptions about people with mental illness. My narrative also gave people hope, which made me feel useful¹.

■ HUMANS HAVE A NEED TO TELL NARRATIVES

I am aware that telling my narrative puts me in a long line of human storytellers. Human beings have an innate need to construct narratives or stories about their experiences⁴. From the cave drawings in Europe to the Egyptian hieroglyphics to

people sitting around smoky campfires, humankind has utilized storytelling as a means of explaining their lives and their worlds to each other, and to future generations.

In modern times, narratives continue to hold an important place in people's lives. The Danish writer, Isak Denison, famously said, "to be a person is to have a story to tell"⁴. As it is widely known, popular culture bombards us with a seemingly endless number of stories. TV, magazines, movies and new technology i.e. the Internet, Facebook, Twitter, YouTube, etc. provide a constant barrage of narratives while giving us opportunities to tell our own stories to friends and strangers alike.

■ STIGMATIZING AND COMPETING STORIES ABOUT THE MENTALLY ILL

When it comes to narratives of people with mental illness, popular culture through the mass media stigmatizes people with mental illnesses by depicting them as ax murderers, serial killers, etc.⁵. Such negative stereotypical images reinforce popularly held misconceptions that people with mental illnesses are dangerous, of weak character, or even evil. These negative and inaccurate stereotypes fall hard on individuals with mental illness, who often, unknowingly, internalize them and withdraw from adverse social contact feeling 'less than' or inferior to other people^{6,7}.

The mental health field is a domain where competing narratives can also undermine the mentally disabled person's dignity and self-image⁸. Psychiatrists tell the story of an ill person through a given diagnosis, the symptoms of the illness, and need for medication and talk therapy, and in extremity the need for hospitalization. The psychiatrist's prognosis is typically that of a long-term degenerative disorder for people with schizophrenia, and only somewhat less pessimistic about other mental disorders. When the person complies with her/his treatment, she/he is considered a good patient. When he/she is a non-compliant, she/he is thought of as a bad patient or 'treatment resistant.'

The clinician's narrative follows the psychiatrist's regimen and adds several additional elements: identification of the patient's 'problems' brought on by the illness (to be solved by the patient and the clinician working together); the setting of goals (often the clinician's goals, not the patient's); and a treatment plan for addressing and solving problems⁸. Again, the compliant patient is considered to be a good one, the non-compliant is the bad or rebellious one, with the onus landing on the patient, not the clinician.

The user's family tends to construct their own demeaning narrative of their ill relative, trying to make the person

follow the regimen the doctor has laid down. Because the popular myth still holds that "mental illness is brought on by bad parenting"^{6,9}, the user's family is often ashamed to have a family member with a psychiatric illness. The family often views the illness and the disabled member as unable to shoulder her/his responsibilities in the household, thus becoming a burden on the family. For family peace and harmony, they often insist that the ill member follow the doctor's orders and take the prescribed medication⁹. When the user refuses to follow the doctor and family's regimen, such individual is often infantilized as a 'bad girl' or boy or childish. Users sometimes view this pressure from the family as an unfair violation of their privacy, and it is a source of much friction within the family.

In the face of media's stigmatizing images and the competing, often deflating narratives in the mental health field and in the family, the disabled user's sense of self is overwhelmed and often thrust into deep shame, confusion, anger, and silence. The user's own experience is often ignored or downplayed. For example, the prescribed medication may produce unwanted side effects. However, the user's complaints about the unpleasant side effects may go unheard or are minimized by the family who may tell the person that he/she needs to give the medication time to work, or that having a few side effects is better than say, hearing voices. Thus, the user's voice, experience, and wishes are devalued or ignored. User-written narratives provide an opportunity to break the silence and isolation, and express the shame and anger that often accompany such illness¹⁰.

■ TEACHING NARRATIVES TO A COMMUNITY COLLEGE CLASS OF USERS

For four years, I taught at a community college course, "Peer Employment Training", in which the students, most of whom had a mental illness, and many of whom had addiction problems, too, learn to write and tell their narratives. The course is designed to provide users, who aspire to work in the mental health field, the skills they need to help others who are not as far along in their recoveries. The module of the course, "Telling Your Recovery Narrative," is the most dramatic class of the term and causes the students to bond together in solidarity^{4,11}. The course takes off after this class.

Before the students wrote out their narratives, for homework, I told them my narrative in ten minutes or so and then I listened to their feedback. Later, I outlined for them several salient points to focus on and a framework for writing out their own narratives that is derived from the text, "The Peer Employment Training Workbook"¹¹, including:

- a few of my past struggles and how I found and used my strengths to survive them;
- the turning points and experiences that led to hope and important changes;
- the tools used to take charge in tough times; and
- the strengths discovered within myself that pulled me forward;

The day of telling the narratives, I give the class a few more guidelines from the “Peer Employment Training Workbook” for responding to the narratives:

- don’t ask questions;
- make supportive comments only;
- tell how the story inspired hope in you; and
- honor confidentiality.

These narratives challenge my students to reclaim their experiences from the competing ones in the media and popular culture, and from the debilitating effects of their illnesses and oftentimes their horrific early lives. They allow the students to assert themselves and speak openly of their experiences. The students call this: “speaking their truth.” Larry Davidson and John Strauss captured this sense of subjectivity in their article, “Sense of Self in Recovery from Severe Mental Illness”^{12,13}.

These narrations not only break the student’s anonymity but also thrusts him/her out of isolation^{5,14}. They put her/him in intimate contact with fellow students who, going through a similar process, recognize each other in their struggles and hardships, but also in their courage and persistence.

The students’ narratives all reflect their unique journey of recovery but there are often commonalities in the ‘stages of recovery’, or as Patricia Deegan, a leader in the national recovery movement, has written: “We rebuilt our lives on the three cornerstones of recovery — hope, willingness to act, and taking responsible action. We learned to say, ‘I am hopeful,’ ‘I am willing to try,’ and ‘I discover that I can do’”¹⁵.

In the class I teach, students hear familiar stories of trauma and abuse and long periods of inactivity, hopelessness, isolation and despair following the onset of the illness. However, they also hear that there was someone who held the hope for them when they were hopeless and had lost faith in themselves. With hope regained, they find in themselves a willingness to act, which is initially in the company of a friend, family member or provider but later increasingly on their own. This is followed by taking personal responsibility for moving their life forward i.e. finding a part-time job, taking classes, becoming an active member at a day program or clubhouse, connecting with positive people, engaging in meaningful activities, and perhaps going to 12-step meetings. What is

important about these stories is that each person’s recovery path is unique to them^{5,16}.

The stories reveal that while there is no ‘cure’ for mental illness, at this time there is a ‘process of recovery’ that each student works out for him/herself and follows on a daily basis in pursuit of her/his mental and physical health — and reclaiming a life for him/herself beyond the illness. This process of recovery is not linear. After advances, there are sometimes setbacks, slips back into substance abuse for some, false starts, failures, and good and bad days. Therefore, the recovery process may appear at times to be two steps forward, one step back^{15,16}.

In short, the students affirm that recovery is a daily process, and it is hard work. Witnessing each other’s victories, what comes through loud and clear is the resilience they see in each other and in themselves. They congratulate each other for the courage it takes to tell their narratives. They affirm each other’s success for reaching the point where they can share their recovery narrative with classmates as part of a college course, for coming so far from where they started out.

In their recovery narratives, they see a victory over the naysayers and those who told them their lives were over once they were diagnosed with a serious mental illness^{10,16}. In each others’ narratives, they recognize their own marginalized lives, second-class citizenship, pariah status among family members, and the friends who rejected them. However, in a group of their peers, these old wounds have a chance to heal as their heroic struggles take on new meaning and purpose. New friendships are formed. Many of the students go on to take other college courses and get degrees. Others get part- and full-time jobs in the mental health system, while others become leaders in day programs and in their tenant associations.

Like the mythical phoenix rising from the ashes into new life, the students’ emergence from the flames and devastation of their illnesses is a thing to be praised, admired and celebrated. No longer outcast or isolated these students feel their triumph, individually, and as a group. Such is the power these narratives have in transforming dire fate into a living story.

■ CONCLUSIONS

The person living with a mental disorder is faced not only with the challenge of the illness, but also with the stigmatizing and competing narratives of the media and mental health field, and in the family in which she/he lives. Presenting a narrative to a group of peers helps the person to reestablish a new and valued sense of self and purpose within and beyond

the limits of the disability. Describing the pain, anguish and disruption in her/his life, the narrative gives rise to suffering, perhaps a new feeling for many users where now “true suffering is marked by an inner peace in knowing that their pain is leading (us) forward into a new future”¹⁵.

As a group experience, the users bear witness to the strength and courage of the storytellers. They see each other not as victims, but as survivors and role models as they seek to cope with their illnesses and reclaim their lives with new-found confidence and hope.

REFERENCES

1. Weingarten R. Learning to accept your illness. NAMI e-advocate. 2012.
2. Goffman E. Stigma, Stigma: Notes on the Management of Spoiled Identity. Simon & Shuster, Inc.: New York London and Toronto; 1963.
3. Murphy RF. The Body Silent, the Different World of the Disabled. Norton Paperback: New York; 1990.
4. Ridgway P, McDaormid. Pathways to Recovery, a Strengths Recovery Self Help Workbook. Auburn Hills, Michigan: Date Reproductions Corporation; 2006, p. 375-395.
5. Corrigan P, Lundin R. Don't Call Me Nuts! Coping with the Stigma of Mental Illness. Champaign, IL: Abana Press; 2001.
6. Wahl O. Mental health consumers' experience of stigma. Schizophrenia Bulletin. 1998;25(3):467-78.
7. Kleinman A. The Illness Narratives: Suffering, Healing and the Human Condition. USA: Basic Books; 1988, 159 p.
8. Vasconcelos EM, Paes Leme CC, Weingarten R, Novaes PR. Reinventando a vida: narrativas de recuperação e convivência com o transtorno mental. Rio de Janeiro/São Paulo: EncantArt/Hucitec; 2006.
9. Deegan PE. Recovering our sense of value after being labeled mentally ill. J Psychosoc Nurs Ment Health Serv. 1993;31(4):7-11.
10. Ashcraft L, Zeeb M., Martin C. Peer Employment Training Workbook. 3rd ed. Phoenix: AZ Recovery Innovations, Inc.; 2007.
11. Davidson L, Strauss JS. Sense of self in recovery from severe mental illness. Br J Med Psychol. 1992;65:131-45.
12. Davidson L, Strauss JS. Beyond the biopsychosocial model: integrating disorder, health and recovery. Psychiatry. 1995;58(1):44-55.
13. Ralph RO. The dynamics of disclosure: its impact on recovery and rehabilitation. Psychiatr Rehabil J. 2002;26(2):165-72.
14. Deegan PE. Recovery: the lived experience of rehabilitation. Psychosoc Rehabil J. 1988;11(4):11-9.
15. Ridgway P, McDiarmid D. Recovery Self Help Workbook. Data Reproductions Corporation, Auburn Hills: Michigan Fourth Printing; 2006.

Received on: 25/10/2012
Accepted on: 28/10/2012