

Living with Mental Health Challenges:
Personal Stories of Recovery from Across the Globe





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## Introduction

## Living with Mental Health Challenges: Personal Stories of Recovery from Across the Globe

#### James M. DuBois\*† & Heidi A. Walsh‡

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**Abstract.** This symposium includes twelve personal narratives from individuals who live with serious mental health challenges that are sometimes diagnosed as schizophrenia, bipolar disorder, major depression, post-traumatic stress disorder, or other conditions. Such challenges are often persistent, lead to stigma and discrimination, and can deeply affect quality of life. Serious mental health challenges are frequently approached as life-long medical conditions, given a diagnosis and treated with medications. However, some pursue non-medical treatments, peer support, use diet and exercise to promote wellness, embrace models of recovery, and function well even when symptoms persist. Approaches often differ across nations, depending upon their resources and philosophy of mental health challenges. Three commentaries on these narratives are also included, authored by experts and scholars in the fields of cultural psychiatry, refugee mental health, human rights advocacy, child's health, and global mental health. We intend this collection of stories to broaden the range of acceptable responses to mental health challenges, raise awareness of stigma and bias in mental health care, and share the wisdom and preferences of those living with mental health challenges.

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Key Words. Medical Ethics, Narratives, Global Mental Health, Shared-Decision Making, Quality of Care

#### Introduction

Ten years ago, the first issue of *Narrative Inquiry in Bioethics* included a collection of stories on "Experiences of Psychiatric Hospitalization." These were stories from the United States. They were powerful,

brave stories from people who—voluntarily or involuntarily—were admitted to a psychiatric care unit to receive care for acute mental health difficulties. The authors differed on important matters, including how helpful they found standard protocols in the United States, which typically involve hospitalization, diagnosis, and medication. Some found the approach helpful. Others lamented the stigma and self-identity changes that come with diagnosis; the side-effects and lack of effectiveness of medications; the trial-and-error approach to finding an effective medication; and the deep sense of loss of control that can accompany in-patient care.

Shared themes also emerged from the symposium, including: the power of kindness to console and provide a sense of safety when you feel most vulnerable; the value of creative activities such as art projects; how peers enhance knowledge and reduce a sense of isolation; and the need for social and economic support when transitioning to independence.

In our efforts to broadly disseminate this original symposium, we shared it with leaders at the Open Society. When Christine Ogaranko, a program officer with their Mental Health and Rights initiative, read through it she proposed that we partner to produce a new symposium. This collection of stories would be global and move beyond the biomedical model to explore a variety of ways that people foster recovery. It is worth explaining what we mean with the term 'recovery,' as it is often the subject of misunderstandings.

People who live with a severe mental health challenges, for example, those who receive a diagnosis of bipolar I or schizophrenia, are often told that there is no cure. The recovery movement does not deny that many mental health challenges accompany people throughout their life; but they insist that recovery is possible. One formal definition of recovery is "the process in which people are able to live, work, learn and participate fully in their communities" (President's New Freedom Commission on Mental Health, 2003, p. 5). As noted by Del vecchio and Blyler (2009), descriptions of recovery from mental health consumers—those living with challenges—are often much richer.

Recovery, as consumers define it, comprises hope, empowerment, social connectedness, meaning/purpose, aspirations, contributions to society, satisfaction with life, building on personal strengths and resources, well-being, positive sense of self, roles and life beyond the mental health system, respect, connections, self-determination, and spiritual development. It is a process/journey, way of life, attitude, or way of approaching the day's challenges rather than a point-in-time outcome; the journey is nonlinear in nature. Not synonymous with cure, mental health recovery may involve ongoing symptoms, treatment, or supports. p. 107

The stories in this symposium are a resounding success in illustrating what recovery can look like and what factors support or thwart recovery in radically different settings.

It would be a mistake to think that this symposium speaks to the needs of a small percentage of the global population. Mental health challenges are common, with estimates of up to 36 percent of the world's population experiencing them during their lifetime (Kessler et al., 2009). Some of these challenges begin in childhood or adolescence and are seriously impairing though they can start at any age across the lifespan, and often when a person experiences adversity, such as violence or poverty (Cosgrove, 2019; Finn, 2017). Many countries neglect to prioritize mental health treatment, and often people who experience mental health challenges are stigmatized by the public, health care providers, and policymakers, which prevents people from seeking help or from being able to obtain it (Mahomed, Bhabha, Stein, & Pūras, 2020). Properly treating mental health challenges could have a significant public health impact on a global scale, considering the number of people who are affected (Kessler et al., 2009).

Recovery from mental health challenges is possible but made more difficult when treatments are limited to pharmaceutical or coercive therapies (e.g., involuntary psychiatric hospitalization) (Pūras & Gooding, 2019). In many parts of the world, people experiencing mental health challenges have little to no access to support or treatments, particularly if they cannot afford them (Klein, 2016). The biomedical approach, which uses pharmaceutical treatments, is arguably overemphasized in the United States and many developed countries. While pharmaceuticals may provide relief to some mental health users, they can also be debilitating (Boyle & Johnstone, 2014; Finn, 2017). Perhaps more importantly, this approach often views normal human

responses to suffering and adversity, such as anxiety and depression, as symptoms of disease (Boyle & Johnstone, 2014; Finn, 2017; Landeweer, Abma, Santegoeds, & Widdershoven, 2009; Mahomed et al., 2020). Further, it does not address the social, cultural, spiritual, or economic factors that can affect mental health (Cosgrove, 2019; Landeweer et al., 2009). Lisa Cosgrove points to the high suicide rate in India, where one-fifth of suicides occur globally. This high rate can be attributed to the number of farmers who are in debt, do not own the land they farm, and can no longer compete with corporate farms that plant genetically modified crops (2019).

Coercive treatments involving involuntary hospitalization or pharmaceuticals administered against a person's wishes may erode trust, cause stress, and damage the patient-provider relationship (Landeweer et al., 2009; Mahomed, 2017). However, pharmaceuticals can be an essential part of treatment when they are prescribed through shared-decision making by a provider that the patient trusts, when they improve symptoms, and when combined with other therapies and approaches that address underlying challenges that exacerbate mental illness (Eaton, 2019; Landeweer et al., 2009).

There is growing support for user-centered and self-directed comprehensive approaches to treatment, which are supported through the lens of human rights, self-advocacy, dignity, shared decision-making, and autonomy (Mahomed et al., 2020). In 2008, the World Health Organization (WHO) outlined a strategy to improve and prioritize global mental health care. The WHO recommended a comprehensive treatment approach that would integrate mental health care into primary care, increase access to pharmaceuticals, and raise public awareness about mental health challenges. The approach would include families and communities in treatment to provide support to mental health users, establish national policies and legislation where there are none (or where improvements could be made), monitor community mental health, and support mental health research (Monteiro, Ndiaye, Blanas, & Ba, 2014).

A focus on psychosocial treatment models that treat the whole person can contribute to wellbeing and health, as can empowering people to

self-advocate and take part in society through work, school, and volunteering (Finn, 2017; Mahomed et al., 2020). Having the support of a community can decrease feelings of loneliness and isolation in people experiencing mental health challenges and help them find meaning in their lives (Cosgrove, 2019; Landeweer et al., 2009). Educating the public and raising awareness about mental health challenges could alleviate some of the individual and societal barriers, such as stigma, which prevents some individuals from seeking help (Mahomed, 2017). Despite some improvement, the adoption of psychosocial treatment models with a focus on human rights and holistic approaches remains low throughout the world (Mahomed et al., 2020).

The NIB editors worked closely with the Open Society Foundation to produce a symposium focused on global mental health that would explore ways of living with mental health problems that go beyond biomedical models, while acknowledging that pharmaceuticals can be useful in improving quality of life and reducing mortality. We aimed to collect stories from international authors who have experienced mental health challenges that describe a wide range of responses such as peer support, self-help, diet and exercise, psychotherapy, and the use of pharmaceuticals under a physician's care. We wanted a global look at mental health experiences as circumstances around the world differ in law and policy, social attitudes toward people who experience mental health challenges, support and the status of available resources and cultural norms surrounding mental health. We sought commentaries from authors with diverse expertise and from diverse nations. With Open Society's help, and by using our networks, we disseminated the call for stories internationally and collected 21 stories from 11 countries. Twelve of those stories are included in this symposium and the other nine are included in the online supplement for this issue.

#### The Call for Stories

The call for stories sought stories from people who have experienced serious mental health challenges and pursued recovery. This issue was planned before the COVID-19 pandemic, and we are especially grateful to the authors for sharing their stories during such a difficult time.

Authors were asked to consider the following questions:

- What sort of mental health challenges have you experienced, and how have they affected your life?
- How have you approached living with or recovering from mental health challenges?
   What has worked well for you? What has not worked well?
- Have you experienced stigma or bias due to your mental health challenges? How has this affected your well-being?
- What advice would you give to someone who is experiencing serious mental health challenges for the first time in their life? What advice would you give to their family, friends, and healthcare providers?

The editors of Narrative Inquiry in Bioethics published the Call for Stories in the NIB newsletter and on the NIB website. Additionally, the call was posted on several social media platforms, including LinkedIn, Facebook, and Twitter. It was distributed through the American Society for Bioethics (ASBH) and the Medical College of Wisconsin (MCW). We also distributed the call through numerous private social media groups, with colleagues and friends living across the world or who do international research, and with the Mental Health Innovation Network. The Open Society Foundation shared the call with its grantees, partners, and staff, the World Health Organization's EQUIP team, United for Global Mental Health, the Pan-African Network of People with Psychosocial Disabilities, and with Mental Health Europe. We also shared the call with many independence centers and clubhouses globally.

#### The Narratives

The stories included in this issue reflect diverse backgrounds, kinds of mental health challenges, and experiences of recovery. The authors provide valuable insight into their challenges, goals, preferences, and supports for continuing care, healing, and above all, meaningful living. Problems flowing from socially-constructed barriers run through the stories, such as clinician attitudes and assumptions, lack of effective communication, siloed systems of medical and rehabilitative care, lack of access to needed supports and services in the community, and the complicated and opaque reimbursement systems that drive treatment and discharge decisions. Despite their challenges, most authors share with readers creative ways that they found solutions through self-advocacy, healthy practices, peer support, or a caring health care provider.

As noted, our aim was to gather a very different set of stories than those published in the very first issue of NIB. In many ways, that goal was achieved: The stories come from 11 different nations, and the theme was recovery rather than hospitalization. Nevertheless, because the mental health challenges that authors face were often very similar, many of the themes are the same. One such theme—picked up by three of our commentators—is expressed succinctly in the story from the De Bry family: "the best medicine is unconditional love."

#### The Commentaries

This symposium also includes three expert commentaries on the narratives. The commentary authors— Dainius Pūras, Linda B. Cottler and James Boehnlein & Mark Kinzie—provide unique perspectives informed and enriched by their expertise in psychiatry, global health, health policy, and improving health care for vulnerable populations.

Dainius Pūras, MD, is a professor of child and adolescent psychiatry and public mental health at Vilnius University, Lithuania. In 2014, Dr. Pūras was appointed by the United Nations Human Rights Council as the UN Special Rapporteur on the right to physical and mental health and was holding this UN mandate until 2020. Dr. Pūras is a human rights advocate with a special focus on the rights of people in vulnerable situations including children and persons with mental disabilities. Since 2018, he has served as director of the Human Rights Monitoring Institute - NGO based in Lithuania.

Linda B. Cottler, Ph.D., MPH, FACE, is Associate Dean for Research at the College of Public Health and Health Professions and Dean's Professor of Epidemiology at the University of Florida (UF). Before moving to UF, Dr. Cottler was at Washington University for 30 years, where she developed a robust research program in addiction and community engagement science. Her research has involved developing culturally reliable and valid measures for identifying substance use, abuse and dependence, along with psychiatric disorders and their risk factors. Her work has had an international focus, extending to Afghanistan, Australia, Haiti, India, Kenya, Taiwan, and Thailand.

James Boehnlein, M.D., M.Sc. and Mark Kinzie, M.D., Ph.D., co-authored a commentary for the symposium. Dr. Boehnlein is Professor of Psychiatry at Oregon Health and Science University and Associate Director for Education at the VA Northwest MIRECC. His career interests have been in cultural psychiatry, evaluation and treatment of PTSD among refugees and Veterans, and medical education across the career spectrum. Dr. Kinzie is Associate Professor of Psychiatry at Oregon Health and Science University and Psychiatry Director of Residency Training. His scholarly interests include refugee mental health, including treatment of survivors of torture.

#### Conclusion

Millions of people develop mental health challenges each year throughout the world. With this collection of stories, we intend to broaden the range of acceptable responses and potential treatments to mental health challenges that recognize cultural and societal considerations. We also aim to raise awareness of stigma and bias in mental health care and share the wisdom and preferences of those living with mental health challenges.

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## **Personal Narratives**

## My Wedding Day

Syrena Oswald

#### Canada

heard the whisper of my name as I stood at the edge of the bridge, gathering up all my courage and strength to jump. After hearing my name repeatedly, I finally yelled with my eyes shut, "Leave me alone!" I kept my eyes closed, spread my arms out like Jesus on the cross, and jumped over 120 feet into the cold river water. Once I hit the water, I felt my body surge with a powerful rush, and as I sank to the bottom, I heard a faint voice telling me to rise. As I came up to the surface, I gasped for air and began to feel panicked. Again, this same peaceful voice told me to lie back and remain calm. And as I floated on the river's surface, I felt the vibrant heat of the sun shining down upon me and felt a peace I had never felt before.

Within minutes I felt the tug of someone grasping at my arm, and they began pulling me towards the shore. Once we got to the shore, I proceeded to tear off all my clothes and stood at the water's edge naked and in shock. After a few minutes, someone wrapped a blanket around me, and then I began to run up to the vehicles calling out my love's name, pulling at the door handles, wondering why I could not find him. My goal in jumping off the bridge was to show my partner how much I loved him and to show God that I was ready to walk down the aisle and become one with God and my love. I wondered where all my family and friends were? Why weren't they here waiting for me? As this was my wedding day. I was so confused.

Little did I know that at that moment, I was at the height of a severe mania and had been hallucinating, delusional, and in a state of profound psychosis. It wasn't too long after I was running around trying to get into vehicles that I was taken into custody by the Royal Canadian Mounted Police and driven to the hospital, where I was admitted into the secure medical unit and later diagnosed with Bipolar 1.

Six months prior, I had been diagnosed with panic attacks and depression, which prompted the psychiatrist to prescribe me antidepressants. Unfortunately, antidepressants can induce mania in patients with bipolar disorder, which I was told by the doctors. It is fair to say that had the previous psychiatrist taken more time to investigate my background, he may have been able to determine that I was, in fact, dealing with bipolar disorder, not just anxiety and depression.

During my month stay at the secure medical unit, I received some good care from the attending psychiatrist, who is now my full-time doctor, and from the team of nurses. However, one incident that occurred during the first week left me traumatized and created a deep sense of shame and left me unable to speak of it for over a year.

During the first few days in the secure medical unit, I was told I slept for days, which seemed reasonable as I had not been sleeping due to the mania. After feeling a little more stable, I recall feeling quite agitated with being isolated from family and friends and wanting desperately to speak with my mother and my best friend. I remember walking out of my room and heading towards the nursing station, where I promptly asked the attending nurses to give me the phone so I could call both my mother and my best friend. The staff refused to do so. I then became incredibly upset and began yelling both my mother's and best friend's phone numbers repeatedly, demanding I be provided a telephone to call them. I was tackled and taken into a small room where I was pinned to the ground and injected with a needle in my butt. Within minutes I was knocked out by the sedative they gave me. When I finally awoke, I was terrified by my surroundings as I was locked up in a 12 by 8-foot room with a small barred window, a metal sink and toilet, and a small mat to lie on. Why was I in here? What had I done? I began yelling for someone to come let me out, but no one would respond. Thoughts of my life began swirling through my head . . . I was a teacher, a good citizen . . . how could I be treated like this . . . like a prisoner? I began to cry in desperation, begging them to hear me, to talk to me, but no one came. This scenario played out for days; with me yelling, begging, crying to be let out and finally, after 3 or 4 days, they put me back into my original room.

This experience brought on a lot of anxiety and shame as memories of past trauma came flooding back to the surface. And although the staff had no way of knowing this about my background, they should never have taken such extreme measures to deal with my situation. There are several ways in which I have learned to move past this experience and give it a voice. And although it still causes me pain to this day, as it always will, I am now able to view it from a lens of compassion and courage.

The first step was taking a stance by interviewing with a local radio station about the inhumane practices, as story after story had been coming out about these types of situations happening at this specific secure medical unit. So, I got the courage to speak on behalf of those who were scared to go public. This created a lot of anxiety, but with the support of family, friends, and a counsellor, I managed to work through it. Anxiety can grip you and provide stories that can leave you paralyzed with fear but I coped by allowing myself to feel the fear and ride the waves of anxiety so I could feel my feelings. This strategy assisted me in providing myself with compassion as the situation was incredibly traumatizing and was not easy for me to talk about. When I did the interview and talked about my experience, I was able to stay calm and focus on what happened but also recognize the positive aspects of my experiences in order to provide an inclusive lens.

Additionally, my involuntary hospitalization resulted in a referral to a local mental health and wellness organization where I took part in an intake process regarding counselling and group therapy. This process took over a year, where I was eventually asked to proceed with another intake interview. A counsellor determined that I was a good fit for a group program called Dialectical Behaviour Therapy (DBT). This therapy group has been instrumental in assisting me in developing skills to recognize and work through my emotions and radically accepting situations for what they are and learn from them. For example, having Bipolar

creates dramatic mood swings for me, which at times leaves me vulnerable to strong emotions that have resulted in detrimental reactions. One of the skills called STOP, prompts a person to literally stop in the moment, observe, and proceed mindfully. I am also working with my psychiatrist in determining what mood-stabilizing medications can assist me in creating balance in the polarities of my disorder. This is an ongoing process due to the presence of comorbidities. Stability has been extremely challenging with various medication changes, mood fluctuations that consist of highs and lows, along with suicidal ideation. Although I continue to have these challenges, I also persevere with therapies, medications, family, and friends.

Lastly, although incredibly traumatizing, my overall experience in the hospital has allowed me to demonstrate my strength to speak out regarding social injustices and bring light to mental health practices that need to change. So, I see this as a blessing in disguise as I would never want anyone ever to have to go through what I did that day. Through my actions and the actions of others, the hospital has been under investigation, and changes are being put into action. This is all I ever wanted, and I hope that with this story, people will have more compassion and courage to speak out and create change to support those with mental health issues.

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#### From Fear to Love

Glenn Roil

#### Canada

have lived with anxiety for most of my life. After going through a very traumatic event about 13 years ago, I now also live with posttraumatic stress disorder. This has affected my relationships with my family and friends. My family did not have any understanding or compassion for what I was dealing with when it came to my mental health challenges.

When I was a teenager, my parents took me to our family physician who asked if there was a history of mental illness in the family. They said there was none on either side. I found out several years later, I did have family members with mental illness, but this was swept under the rug and not spoken about. I was made to feel that I was the "black sheep" in the family and the only person who struggled.

I had a very supportive grandmother who raised me for the first few years of my life, and I bonded with her closer than my own mother. As a quiet, shy boy, I did not have any real friends growing up in school or even a girlfriend in my teens or twenties. I did not have the confidence to talk and make friends with people my own age. I connected better with adults and older people, as I was an old soul. I had little confidence because my parents and family always told me I was not good enough and that I would not amount to anything. Because of this, I was never given an opportunity to go after my passion in life, which hurt my feelings and shattered my confidence.

In school, I was not involved with extra circular activities such as sports or dance to make friends. I did not feel confident to go to work in my teens or twenties and did not work until I was in my 30s and living on my own. Despite still having challenges, I needed to support myself financially. In working, I gained confidence, self-worth, and self-determination. I took my skill set and found a place to live, a way to support myself with a job, and I decided to take responsibility for my mental health and went to my first support group with CHANNAL (Consumers' Health Awareness Network Newfoundland and Labrador). CHANNAL is a nonprofit organization dedicated to supporting and encouraging individuals living with mental health and addiction challenges. I started to develop some good friendships and valuable connections. I found it difficult to deal with emotions in a relationship until I was in my 30's. While trying to maintain my own mental health and wellness, I was also trying to support partners who had significant challenges of their own. Being out of some of these challenging relationships, I have learned more about myself and gained a better perspective of who I want in my life. Not dating in my teenage years or even my twenties may have been a blessing in disguise. Being older and dating, I have the knowledge to reach out to the right supports when I need them. I may not have had the smarts or insights to do this as a young person.

My mental health challenges affected my education, as I hated school. After high school, I started to learn about the investment world and read business biographies by authors like Warren Buffett, Richard Branson, and Bill Gates. I loved reading business magazines like Forbes 400 and Forbes Global Billionaires and the Canadian Business Rich 100 List, and I watch business channels like CNN Financial Network, CNBC, and Fox Business News Channel. Even though school was challenging, and I hated it, I was able to self-teach and learn independently about topics I am passionate about. I believe learning about investing is important for careers, financial independents, and people who have disabilities, or are living in poverty. I believe investing will help them have a better opportunity at a good quality of life. I bought and read a lot of biographies and autobiographies on successful people who had mental health or other challenges. I found it inspiring that they established successful business enterprises and gave back to their community and society despite their struggles and situation. I would like to do the same for my life and my community.

My approach for living with or recovering from a mental health challenge is to have a good outlook on life with hope for positive possibilities. That is how I live every day.

I have turned challenging experiences into positive experiences, both in my personal life and in the community. I speak on my own incredible story to inspire others so that they can have similar positive outcomes in their lives. What has worked well for me is being around other people with similar mental health challenges or issues and staying busy with kind and compassionate people in my work life, volunteer life, and community.

My first piece of advice to someone who is currently struggling with a mental health challenge is to ask your work or community about opportunities

to get involved. Take the initiative and seek out opportunities that align with your passion. You never know where opportunities can take you. Another piece of advice I can give is to do whatever makes you happy in life. I had the opportunity to apply for the Canadian Mental Health Association (CMHA) National Council for Persons with Lived Experience, and I was successfully selected as the NL Representative. As I attended and presented at national and international conferences with CMHA National, I made some valuable connections with national leaders in politics, business, and the community. Because of my work and community involvement, I have met so many great people and made so many friends. I am so happy to have them in my life. This makes my mental health so much more manageable. Some of these great friends, who I call my honourable family, are the people who I experience life events like holidays and birthdays with. We make memories doing other "normal" stuff that families do. Try to find friends who are not only friends but honorary family who are supportive, understanding, compassionate, and accepting.

What has been challenging for me was dealing with my family, who did not understand or accept me or other people facing mental health challenges. My immediate family did not support me when I needed them the most. They did not understand what I and others in the community deal with. For example, when I was a teenager, I was told by family members that I would not be anything in this life. This made me feel valueless and destroyed my confidence that I could be successful in life. I decided to take a positive outlook and made new important connections. I would not agree to medicine that a physician was asking me to take, as I was looking for other options for mental health counselling and support group programs and services. I now have a much better and higher quality of life and have been able to be successful.

Stigma and bias have affected me and my relationships with my immediate family and some romantic relationships. I also felt affected when trying to obtain employment. Some workplaces did not understand or support people with disabilities and mental health. When I first started working,

there was not an understanding or requirement to accommodate employees with mental health challenges or disabilities. With new mental health work legislation across Canada, the USA, and other countries, it is now better for employees. Companies are putting into practice programs such as the CMHA Not Myself Today and the Mental Health Commission of Canada National Psychological and Safety Standards, designed to de-stigmatize mental health challenges and create conversations about mental health in the workplace.

Mental health has affected my well-being, as I have felt less than a person on some days. Some days I feel like I am pushed to my limit, but I keep at it. On really challenging days, I reach out to my supports and practice self-care. Each day provides us with new opportunities, so I try not to get discouraged. Mental illness can sometimes make you overthink and overanalyze. As always, I try to look to the bright side of my life, using my experience and knowledge to help myself, my friends, and others in the community. I have a voice to advocate for myself and make changes to improve the mental health system. My faith has played a critical role in my recovery journey and my personal life.

I have used my experiences with anxiety and PTSD to participate in numerous community initiatives. I heard from so many people in my life and others in society from community, business, and government leaders that it is so brave of me to share my story with the public to help reduce stigma. I encourage everyone struggling to use their lived experience with mental health to educate family or friends. I have learned that my mental health struggles do not define me but make me a more compassionate and understanding person for all people with disabilities. I am a full member of society who is employed, in a loving and caring relationship, and is heavily involved with volunteering to make a better society for everyone.

I have had many positive comments about my public speaking about my story on provincial, national, and international levels at conferences and events. The first time I spoke about my own story was at an event called Motivation Mondays in St. John's, NL, Canada. I was so nervous to speak, but I ended up receiving a standing ovation with over 200 people in the room. From this, I was invited to a joint conference with the Mental Health Commission of Canada and the Canadian Association of Chiefs of Police in Toronto, ON, Canada in March 2014. After that, I was asked to speak at the Community Coalition for Mental Health event in October 2015 in St. John's, NL, Canada for an audience of 1300 people. I received praise from the NL Deputy Premier and Minister of Health and Community Services and many individuals with mental health challenges for my speaking.

At the Peer Support Canada Conference in May 2018 in Calgary, Alberta, Canada, I had a great experience sharing my story with people with mental health challenges and other professionals and fellow mental health advocates. At the CMHA National Mental Health Conference in October 2018, in Montreal, Quebec, Canada, I made arrangements to have the Canadian Federal Health Minister meet with the CMHA NCPLE for a period of an hour and have pictures with her. When I was at the Canadian Mental Health Association National Mental Health Conference in September 2019 in Toronto, Ontario I had the opportunity to meet Dr. Vikam Patral, a Harvard University Professor who is passionate about engaging people with lived experiences in his international mental health research and work. I have also been very involved in my community, working with the Janeway Children's Miracle Network Telethon, the Cornerstone Ministry Center Supper Bowl Food Ministry, and the Rogers, Rogers Moyse Christmas Community Dinner. I have been a strong mental health advocate, involved with mental health policy changes and legislation for the Mental Health Care and Treatment Act and new mental health programs and services like DoorWays, a walk-in clinic for mental health services. My most proud accomplishment to date is when I received a personal letter from President Barack Obama in 2014 encouraging me to continue with my mental health advocacy work and aligning himself with my beliefs and passion.

Sometimes all I needed was to have someone listen and not push me to do anything or offer advice unless I have asked. I have felt empowered making decisions on my own about my mental health care, my career opportunities, and my personal life. I have become what I wanted in life with my career, my mental health advocacy work, and my volunteering in the community.

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### A Voice of Hope for Mental Health in Cambodia

Bunna Phoeun & Fr Kevin Conroy

#### Cambodia

"Stigma and limited knowledge on mental health leave me to live with fear and prolonged treatment."

₹veryone should have knowledge about mental health so that we can understand ■ their problems and know where to look for support for them. I did not know what was wrong with me. Reflecting on my illness, it took me a long time to find the right treatment.

In 2018, I was diagnosed with schizoaffective disorder by a psychiatrist. I did not know what schizoaffective disorder or mental illness was. The doctor told me that I had a mental problem (sa sai brasaeat)—that I have to take psychiatric medications. (Sa sa sai brasaeat refers to brain or neuron problems, a common word used to label people with mental illness. It is stronger and more stigmatizing than the word "rok chet".) I was shocked because I thought I just had a different personality from other people.

After graduating from university in late 2016, I changed my job to be an accounting assistant. The company didn't have a clear accounting system yet. I thought that the lack of a system added to my stressful atmosphere at home. I decided to quit the job and look for a new job. I knew that finding a job is difficult and even more challenging for a person like me. I don't talk much. The psychologist

told me I'm introverted. After applying for various positions, I got a call for an interview from a Catholic Organization. I passed the interview and was offered the job. I thought the new job could help me feel better.

However, I still felt the same. I felt restless, uneasy, fearful, and tense, especially when there was a group meeting. During a Christmas gathering in 2017, the organization planned an annual 4-day staff meeting. I started to feel uneasy and anxious. On the second day, I started feeling fearful and lonely. I kept worrying about how I could perform well throughout the day. On day 3, the group was on a trip to an island. During the trip, I thought about what to do, what to say, how I should behave when eating and sleeping by the sea. These thoughts kept bothering me all the time. Sometimes, I cried without reason. One day, I went with my colleagues to the beach to have some cocktails. There were eight of us. I was very happy but suddenly my mood changed. I felt down and really sad. Immediately, I wanted to cry but I could not do that in front of them. One of them noticed that I was sad and asked me, "what happened?" I responded, "I am homesick." Inside, I wanted to escape from them and from that place. In my mind, I thought "they think I am a person with rok chet." (Rok chet refers to psychopathology.)

I was not confident or brave enough to tell them about my situation. I was so worried that they would think I am a psychopath. At night, I was still awake. I saw three of my colleagues talking with each other. I heard their voices. They were talking about me. They said, "She is not flexible under the circumstances." I thought about this statement throughout the night. It disturbed my sleep. I felt unwell the next day. On the way back with about 100 people, I wanted to shake the ground to escape from them, but all that could be done was to find a seat at the least crowded table. Because of the poor interactions between them and me I was resentful and angry with them. I felt they did not treat me well and fairly compared to others in the group.

In December 2017, my problems started getting worse. I started to be afraid to face people when I went out. I was afraid of public places. I could not

talk much. I was scared and I could not sleep. I had nightmares. I felt things were going wrong, like a war stirring up people. I started to feel I was being watched by people everywhere I went. I decided to withdraw all my money from the bank and kept it with me. When I returned home, I told my friend, crying like it was my last word before dying. I went through that night without sleeping and started to hear voices. I heard mixed voices, the sound of cooking, a rooster crowing, and other voices that I never heard before. That morning, I realized that I could not work, but I still rode my motorcycle to my workplace. As I rode, I felt and saw black and colorful figures riding behind me. I thought some of them had bad intentions against me, and some were good to me. At breakfast at my workplace, I cried without reason. A Catholic priest, whom everyone calls Father, approached me and asked what happened. I replied that I was getting sick. I saw two old women that were sitting at the same table with me. One of them was holding a knife. She said, "If you dare to walk in, we will stab you to death!" I was not sure if what I heard was true because I thought she was on my side. I also heard voices from another woman. She was making fun of me. I thought she was one of those people who had bad intentions for my family and me. She came into my office and continued to mock me. Afterwards, she left my room. I immediately followed her and begged her not to hurt my family. The woman tried to walk away from me and she acted like nothing happened, but I thought she got out to spy on me and my family.

For now, I think it's not true. What happened it was a sign or symptom of my illness that I did not know before. Again, immediately after the interaction with that woman, a Korean volunteer approached me and passed an item to me. I cried and I did not receive that item. I assumed it was a bomb. I started to panic and hurried to see Father for help. He tried to comfort me and then took me inside the church before he left. While I was sitting there, I thought of many things and my mind was full of confusion. I cried out in the church for a while. Afterward, the same woman came to me and lightly touched my shoulder, which made me cry

even harder. I spent about eight hours crying inside the church. I had no idea why I cried so long. My feelings were once hopeful, now hopeless, floating, and complicated. I was so stubborn.

I did not want to leave the room until one of my colleagues came and comforted me. I was taken care of by my colleagues and the Father. They called my mother and wanted me to talk to her. I did not want to talk to her because I thought all people I saw and the voices I heard were fake. About an hour later, my aunt and her husband arrived. She called me to follow her. I did not answer because I did not recognize their faces. They tried to talk to me for a while. Finally, I decided to go with them. They also brought my finance manager. The driver took me to my aunt's house at Kampong Speu province.

Though I had experienced many problems related to my behaviors, I did not know that they were signs of mental illness. Of course, this problem has had a profound negative impact on my life, professionally and personally. I find it hard to trust anyone, including my relatives. I always suspect that they have bad intentions towards me. For instance, I suspected my aunt and uncle tried to kill me. In 2018, they organized a family trip. They wanted me to relax and feel better. However, in my mind I thought that they were plotting to kill me. Because of those thoughts, I could not sleep. I started hearing voices and seeing fingers reaching out, trying to squeeze my neck.

Before receiving medical treatment from a psychiatrist, I was referred to see four different traditional healers. My aunt took me to see a traditional healer that lives about a kilometer from her house. The healer organized his ceremony. He chanted (saut mont oaea kom) and sprayed perfume on my head. (Saut mont oaea kom is magic speaks in order to push ghosts away from inside the body.) I started to get angry and shouted at him, "I do not like perfume," but he continued his ceremony and blessed the magic water on me. I escaped to sit on the tricycle, hugging my black bag. I noticed I only like the color black. I returned home with my mother and my aunt's family.

I slept with wet clothes and kept thinking many things until late at night. Then, I saw a man. He lifted a knife, and spun it around. He put a white cloth on my mosquito net. The next morning, my family brought me to meet the same healer. I felt that the treatment with the traditional healer was not helpful and caused me more problems. Some traditional healers I went to used a massage stick (chheu massaa), burned and sprayed the perfume, which was meant to get ghosts or evils away from my body. My mother and aunt were worried that I had issues with my brain, so they took me to see a doctor in Thailand to have my head scanned. The doctor said my head was fine.

Due to this illness, I had to stop working for a while. I was depressed, and I often take other people's words into consideration. At that time, I could not eat properly due to loss of appetite. I lost weight. It was hard for me to live in this condition. Sometimes living for a day is like a year. Although my friends have shown that they care about me and do not discriminate against me, I know they are afraid of me.

I started to understand my problems when I met a psychiatrist and a psychologist. The psychologist told me that I might have mental health problems, which have led to paranoid thoughts, sleeping problems, irritability, depression, hallucinations, delusions, social isolation, difficulty concentrating, mood swings, and suicidal thoughts. After hearing the diagnosis from the psychologist. I totally agreed with him. I experienced all the symptoms he presented to me. I became more alert and got annoyed by delusions and hallucinations. I almost died because of a suicidal attempt. I have attempted suicide twice by taking all the paracetamol pills. Another time, I tried to hurt myself by drinking hot water, imagining that I swallowed rat poison. During the treatment with the psychiatrist, I was told to stop working and stay home because the psychiatrist and my boss believed that I could no longer work. As a result, I spent six months at home. It helped me feel a bit better because I did not need to think or worry about my work. Consequently, I also felt depressed because I did not make regular income to support my living expenses and monthly medication costs. I was isolated and could not socialize. Some friends had mixed feelings towards me. Staying at home was like being locked at home. After six months on the medication, I told the Father that I got better and wanted to go back to work. He and the finance manager did not seem to trust me yet. They did not want me to go back to work because the psychiatrist advised me to continue to stay home. I was eager to get a job. I went to see another psychiatrist and a psychologist who allowed me to go back to work. My colleagues, especially my manager, are very supportive.

Here's what I have learned from this journey: a) follow your doctor's instructions and take medicines regularly, b) set time for meals and sleep, c) get advice from the psychologist. I have learned from the psychologist: to be myself and accept myself the way I am. I learned to motivate myself and manage my problems. Also, I recognized that my illness needs extended treatment. Sometimes my symptoms reoccur, but I can ground myself to reality. I listen to Dharma, practice short mindfulness, observe my mood, read, do regular exercise, and give myself a chance to do what I can do. I do not entirely depend on medication.

I have developed a positive statement about myself "I am fine! I can manage it, and it is not real." I committed not to hurt myself anymore. I wish to tell this story so that parents who have children living with mental health challenges understand children's problems and the cause of the illness better. Instead of blaming or putting more pressure on their children, they should listen attentively. Parents should also pay more attention and have warm relationships with their children. Parents should seek professional help from experts such as counselors. They may be able to help children find a way to help themselves rather than taking medications.

Please stay hopeful and your problems will improve. Try to talk to someone you trust if you feel suicidal. My mother motivated me to stay alive. I survive because I want to help others. I wish to tell doctors to give me more explanations about my illness. I want to understand its conditions and choices I can make. I also wish medical professionals would provide more care and empathy to their patients.

## It Is Never Too Late to Turn the Page and **Rewrite the Story of Your Life**

Konstantinos Manthos

Translation by Eleni Chatzopoulou

#### Greece

am suffering from schizophrenia and I dare to say that from time to time this can be very challenging for me. I live in Amfissa, a town in the prefecture of Sterea Ellada in Greece. The majority of the citizens in the town where I live treat me gently and respectfully. On the other hand, some people refuse to talk to me or even mistreat me due to my mental health issues. I could say that this behavior can be so painful for me that I could compare it to the pain of physical violence. This behavior affects me deeply as it makes me recall the behavior of my parents.

My parents were very violent against me, both physically and verbally. I accepted maltreatment during my childhood and my adolescent years. My father was cursing me, insulting me, hitting me at the first chance. During my adolescence, I found the courage to resist and defend myself. I made my own rebellion. The violence that I accepted during these years affects my decision not to create my own family. I was afraid that I could treat my own children in the same way. I could not tolerate this thought. I am still fighting with these past experiences, and I am really proud of myself because I have never been violent against any human being during my life. I consider this as a personal win—a huge success for my own wellbeing.

Living with mental health issues can be very difficult. However, many things helped and empowered me during all these years. First of all, I consider friendship as one of the most important values in my life. Everybody needs a companion in their life. Friendship can make the painful experiences more tolerable, can reduce the fear that I may feel. Friends give me the courage to continue living in a more entertaining way, and give me an outlet in my routine.

Good communication and acceptance from the members of the community where I live improve my self-esteem. I enjoy being in contact with other people, socializing, talking about my interests, such as my love for pets and exercise. I am used to talking to other people about my experiences. This helps me to comprehend my own feelings and thoughts.

I consider exercise as a beneficial activity to face anxiety and stress. Exercising in a systematic way helps me improve my fitness and wellbeing, motivates me to take care of my health and diet, and improves my self-esteem. Generally, I believe that people need motives in their lives to improve, get over their weaknesses, and feel more satisfied. I used to be in a bodybuilding club when I lived in Germany. During this time, I felt very strong and fearless. I could defend myself in an emergency case. I would say that gymnastics is a synonym for power for me.

Fitness is one part of wellbeing. The other part is related to self-awareness. Religion helps me to acknowledge my feelings and my own mistakes. I have CDs of sermons that I listen to every afternoon. These sermons help me to have insight into my behavior. I consider repentance very important in my life. I found the strength to ask God for forgiveness, and I try to find the courage to forgive every person who has mistreated me in the past, including my parents. I believe that forgiveness is a gesture of greatness that helps us turn the page into our lives and continue living more peacefully and happily.

My advice to people who may face mental health issues for the first time is to be patient and determined. Their medicine will help them face their difficulties. Their faith in God and church attendance will help them experience inner peace. They need to think of their life as an open book, which they should read. Every chapter is important because it is a part of our personal story. Every chapter, even the darkest one, can give us the strength to continue our lives, turn the page, and restart.

My advice to parents who have children with mental health problems is to love them unconditionally. Violence cannot be the answer to any situation. Violent behaviors can be very painful and traumatic for children and stigmatize them for the rest of their lives. Parents may regret their past behavior in the future, but this may not be enough to improve their children's wellbeing.

My advice to mental health professionals is to be caring and give the people who suffer from mental health problems a chance to feel accepted and loved. They need to avoid any prejudice and stigma in their contact with people with mental health problems.

In conclusion, I consider sharing my story in Narrative Inquiry in Bioethics as a great opportunity. I can talk about my experiences, thoughts, and beliefs. Moreover, discussing mental health challenges is the only way to fight bias and stigma. I hope this story motivates other people who experience mental health issues to find the strength to face their difficulties.

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#### **Depression: One Person's Perspective**

Craig Marchant

Australia

y name is Craig Marchant. I'm 39 years old, and I have suffered from depression and anxiety since the age of 12. When I was 17, I experienced my first hallucinations, which marked the start of the psychotic elements of my illness. It would take another four years before I was diagnosed correctly with depression/anxiety and schizoaffective disorder and to start active treatment, including medications and therapy.

I can precisely pinpoint the start of my depression and anxiety. It started with the death of my Grandfather on Fathers Day of 1993. You see, I held myself directly responsible for this tragedy. Why, might you be asking? This day, I had the choice of spending it with my Grandfather or seeing my Dad play in the Grand finals for Football (NRL for those Australians amongst us). Generally, I wasn't much of a football guy and would usually avoid it—but

I reasoned that since it was Father's Day and it was the grand finals, I should be going to support Dad. So that's what I did. My grandmother was at a Girl Guides meeting, and the rest of us were supporting Dad, so that left Grandfather on his own.

We aren't 100% sure what happened, but we know that he must have been feeling somewhat unwell and took himself off to bed to nap. He didn't wake up from that snooze. He suffered a massive heart attack and died in his sleep. The next part is a little hazy, but somehow I ended up at my grandparent's place. I believe Grandma was already there, but Mum wasn't yet. When she did arrive, however, I do remember her howl of anguish. I remember seeing Grandpa lying in his bed, with his arm outstretched. I reached out, and he was rock solid and cold to the touch.

Our local GP, who saw all of us in the family, later told me that it wouldn't have mattered if I had been there or not. There was nothing anybody could have done for him. It was so severe. But you try getting a 12 year old to understand and accept that.

I was hospitalised for a week or so, either during year six or year seven. I was blacking out and nobody could give a satisfactory explanation as to what was going on. They performed every test they could think of, but nothing showed up. I remember mum at one stage asking the doctor if it could be depression, but he replied that children my age didn't get depression. Ha! If only.

It was around my 21st birthday that everything finally caught up with me and I started to attempt suicide. Sometimes it was deliberate; I just wanted out of this unrelenting, unforgiving, and perpetual sadness. Other times I didn't even realise what I was doing until 10 or 15 minutes later when I would suddenly come-to and learn what I had done. Of course, it didn't help that I was suffering from the psychotic symptoms such as hallucinations, both audio and visual. I was on a first-name basis with the nurses at the local hospital, not something to aspire to, but it is what it is.

I recall the first time I ended up in the hospital; one of the doctors came in and had a chat and organised some help. I can't remember the exact time frame that passed, but the same doctor came back to talk with me during my second hospitalisation. He said something to me, that while it might sound bad, he endeared me to him from then on and became my GP. He told me that he thought I was seeking attention on my first hospitalisation, but that he now realised how wrong he had been and realised I was in serious trouble. It wasn't that he thought I was an attention seeker that drew me to him. It was the simple fact that there was a doctor who now realised he had been wrong and was willing to admit that to both himself and his patient. Such a doctor is a rare find I feel, don't let them go when you do find them.

It was after one such attempt, when I was a little more successful than usual, that I ended up in the ICU unit of the hospital. I say successful because there was some concern that I might have actually done some significant damage to myself and hence warranted the ICU for 24 hours minimum. It would have been just like any other hospitalisation to me; however, this time, something happened, which gave me a new perspective on life.

I overheard a conversation between one of the nurses and an elderly gentleman who was a couple of beds up from me. While I couldn't hear everything, I clearly remember hearing the older gentleman saying that he wasn't ready to die yet. He wanted to live. In that exact moment, a sobering reality intruded on my thought process. Here I was, in a room surrounded by people who were clinging to life and fighting hard to remain, and I was the sole exception. I was trying to exit stage left. I wept, not only for myself but for that older gentleman. He passed away during the night, so I was never able to thank him for the wake-up call he delivered so innocently. He penetrated my armour and the walls that I had built ever so high, more than anyone ever had—professional or otherwise. I concluded that from that moment on, I would no longer be attempting to take my own life.

It took several years, but eventually, I got myself to an OK place, and I felt that I could finally include a partner in my life. I met my first wife in 2005, and eventually, we got married. We had three beautiful children together, and while our marriage didn't last the distance, I'm still very grateful for what I have.

I met my second wife in 2011, and we got married, and now I have another two little boys, who are livewires and exude so much energy that I feel tired in their presence sometimes. But boy, do I love them so much.

Since I was 15—even younger with my own computer hardware business—I've been working on a near-constant basis, selling computers to friends and family. Since then, I think the most time I've not had a job or worked is six months. It's been a constant challenge for me, but I found working has given me purpose and perspective. Not everyone was aware of my mental health challenges, as I became very adept at hiding it. What was shown on the outside does not reflect the inner turmoil that was always present.

I started out working at our local supermarket. I worked there for many years before I started working full time in the IT Industry. I've held many jobs over the years, from computer hardware technician up to chief technical officer and chief development officer for a large privately owned web hosting and domain names company here in Australia. I've had a very successful career in the information technology sector, and I've enjoyed the challenges presented.

Fast forward to the year 2015; I was running a very successful company with some friends as the chief technical officer and chief development officer. Over the last few years, I had noticed that I was a bit more disconnected than I was usually. I had been speaking with Mum, and she had told me all about her bike ride for charity—Plan's Ride For The Girls. She told me how much she learned about herself and grew, and I decided that this was something that perhaps would benefit me as well.

I looked around at the various adventures on offer and finally settled on something that I could get behind. I signed up to do the Inca Trai in Peru on behalf of the Leukemia Foundation here in Australia. I had supported them before, and this seemed like a worthy charity to me. We were scheduled to leave in May of 2016, and as I had signed up in November 2015, I knew I had to get my skates on from both a fundraising point of view and getting myself into training for the big trek.

May of 2016 came along, and the team headed for Peru and the Inca Trail. It was one of the most memorable experiences of my life, and another one of those startling revelations happened to me while undertaking the Inca trail. It was the second day, and we were a few hours in. I felt physically awful, and my brain was screaming at me that I couldn't do this-who the hell did I think I was? It was our guide Jimmy that helped me more than he may have realised. He said to me that he had seen bigger and heavier people complete the Inca Trail before and that he believed I could do this. I hadn't ever had anyone tell me, outside of the family, that they believed in me. Those words were like rocket fuel to me, and I continued onwards. When I finally completed the Inca Trail—the feeling was utterly amazing. I had done it. Even when I thought I could not, I had achieved what I set out to do. The realisation that I could honestly do anything when I set my mind to it was the most important thing to come out from the Inca Trail.

Arriving back home, I felt this disconnect again at work. It wasn't that the job or position or, indeed, friendships had changed; I had changed. My priorities were different; the things that mattered to me were different. I finished up with the company in 2017 and started looking for my next big challenge. I settled on doing something that could help others, and that was by writing my own story for others to read and hopefully be inspired by and becoming a mental health advocate—speaking for those who couldn't do it. I also decided to partake in a Professional Speakers Bootcamp to get over my fear of public speaking. I reasoned that if I could again speak about my story and mental health, that would be of great benefit for others. I conquered my fear of public speaking, and I've been busy ever since.

There is so much I could include in this story, but there isn't room for it. So many things have happened that have helped shape me into the person I am today. As I want to give an accurate picture of my mental health, I still struggle with this. I have schizoaffective disorder bipolar type, which means some days are amazing, and I can take on the world. Some days are just average, and then some others are the pits. I occasionally fall back into the bottomless, dark pit of despair and have to pull myself back out again. What real choice do I have? I promised myself long ago that I wouldn't attempt suicide anymore, and that's a promise I've held—even with the horrible suicidal ideations that happen regularly. I have a family who depends on me, and I want to see my kids grow up.

If I can finish by saying this to you, don't ever give up hope for a better future. What we live with, what we go through—a lot of people will never truly understand. They may be able to empathise with us, but never truly 100% understand. I know, and more importantly, I believe in you! In time, I hope you can believe as well.

3

## **Learning How to Take Care of the** Otherness of Myself

Anonymous One

## Colombia

ou should be able to go deeper into what you feel, not into what you think. You L have been stagnant for several months because you refuse to feel," Doctor Altea1 told me. "The boy is my husband and I am the dog," I answered, crying. We were talking about the motivations that led me to comment on the movie Isle of Dogs. "In the bath scene, the boy gives the dog dignity through his selfless love. That is what has happened to me: I have been able to heal because I allowed myself to bond." Being able to cry is a blessing. There was a time when I couldn't feel anything.

Thirteen years ago, I was in a black hole in my hometown, Bogotá, Colombia. A deep depression

had settled in me. I had become a dark and cold shadow. My body felt like it was a useless filter between me and the world. I was unable to store experiences anymore, like a camera without a memory card. I can't remember many things from that period. The benzodiazepines also had anesthetized me. Even my senses stopped working. One day, I wanted to discuss the movie Kill Bill with my brother. I told him that I didn't understand the purpose of making it in black and white. "Black and white? That film is in color!" He said. My world had become a gray place.

From a very young age, I began to consult psychiatrists. I was not even four years old when my mother decided to get a consult because I refused to eat. Later, my parents took me to a psychologist because I used to suck my thumb. During my teens, after finishing high school, I consulted again because I was very angry with my classmates and my teachers. I had gone from being a popular and extroverted girl to being an introverted and absorbed person. I felt like living in the absurd. The familiar felt strange, alien, and unreal.

I changed my tastes a lot, so I changed careers and boyfriends many times. Every time a romantic relationship ended, it was as if someone was ripping my skin off. I used to spend long periods not sleeping or eating until a new boyfriend arrived. Then I quickly switched from darkness to euphoria and repetition. Every cycle lasted about a year.

As well as with careers, boyfriends, and therapists, I also frequently changed jobs. Nothing I did was enough despite my best efforts. During my early adulthood, I used to diet because I felt my body didn't fit me. I was so physically tired that I had to gather the strength to change the TV channel. I consulted Doctor Cordelia, a psychiatrist from my health insurance. Every session would last 15 minutes. She diagnosed me with chronic fatigue syndrome. "It's nothing serious," she told me. She prescribed Clonazepam and then Triazolam. In each appointment, she needed to increase the dose and add more medications to my prescription (Fluoxetine, Sertraline, Mirtazapine, Escitalopram). Still, she did not seem to care about my blackouts. She insisted that the medication would be enough.

<sup>&</sup>lt;sup>1</sup> All the names that appear in this story have been changed to protect the identity of individuals.

I began to feel like being caught in a web where black spiders were going to eat me alive.

I tried to read self-help books from authors like Rhonda Byrne or Osho. According to them, to be happy, I only had to ask the universe and all my wishes would come true. I tried homeopathy, acupuncture, and other alternative medicines. I even consulted witches who read tarot or cigarettes (they read your future looking at the shape of the ashes as the cigarette burns) in hopes of hearing that someone was going to save me. Nothing worked. On the contrary, anything "magical" was frustrating. If it was so easy, why couldn't I do it?

I also saw one of my anthropology professors who described himself as an unconventional psychoanalyst. There was no improvement either. I was ashamed because I was living with my parents and I had no job, being no longer able to work. I then enrolled in a course on how to get a job and I took several psychological tests. When the results came out, they told me that I could never work properly. They did not explain why, but they asked me to drop the course. During that time, I also went to another psychiatrist, Doctor Aparicio. He was very recognized and my father paid for him. His discomfort with me was evident because, in each session, he was quick to tell me that the time was up. After three months, he concluded that I should go abroad, which I did, to Argentina. Nevertheless, things got worse there, and I came back to my home city just after three months. I secretly consulted Doctor Cordelia again because I knew she would keep on giving me benzodiazepine prescriptions.

My days passed slowly and I struggled to survive the unbearable seconds that seemed to stretch into a heavier time. I smoked one cigarette after another, waiting to take more benzodiazepines. I endured this prison by reading stories of addicts, depressives, and victims of heinous crimes. It was the time when narratives about kidnapping experiences in Colombia circulated. I found a place for myself in their narratives because an internal monster that diminished and cornered my inner self had kidnapped me. I also began to repeat over and over the lyrics of some songs that expressed how the emptiness felt. I remember my voice shaking.

Then a smoke. Another song, another cigarette. Then a Rivotril.

I decided that I would swallow a bottle of Triazolam. I can't remember how I got to the Olimpia mental health clinic, but I recall signing a disclaimer form to be admitted. I did not accept it because I had no way to pay, and I didn't want my parents to know. However, it was the first time I felt that someone took me seriously, so I came back a few days later. That is how I met Doctor Salvador. He was part of an outpatient program that I could pay with the allowance that my father still gave me.

Knowing that I had bipolar disorder and borderline personality disorder (BPD) was the first step towards my recovery. Finally, someone put a name on my condition so it became true for other people, like my family. Doctor Salvador removed my benzodiazepines and prescribed me Bupropion, Quetiapine, and Lamotrigine. It was a cocktail that came with undesirable effects, but I wanted to stick to the treatment because Salvador was the first doctor who really connected with my suffering. I trusted him. Once, he called me to cancel an appointment, and I started crying. He was able to feel that I was tearing apart, so he rearranged his schedule to see me that same day. I felt that he reacted empathically to my feelings and recognized that I was not exaggerating. He believed me. Before him, I screamed for help, but no one was paying attention. It was just background noise.

During the time under Salvador's care, I used purgatives and made marks on my body. I didn't understand why, although I felt better, those behaviors were unleashed. Doctor Salvador ordered my hospitalization and an ECT process. I sold my car so that I could pay for it. My recovery became my priority.

I spent two years in psychodynamic therapy with Doctor Salvador until he referred me to Doctor Altea, my current psychoanalyst. I have been with her for almost ten years, nine off meds. My psychoanalysis has been slow and it has had its flaws. When I started, with four sessions a week, I assumed I was a lost cause. At first, I refused to lie down on the divan and I used to get very angry when I had to pay her. Once, she got sick and she

canceled my appointment, so I accused her of being unprofessional. That was harsh of me. However, little by little, I learned to forgive her and, incidentally, to forgive myself. I knew it was kinder and even fun to tolerate imperfection.

Did I mention that Altea is married to Salvador? I know that some may say there was a conflict of interest. For me, the fact that Salvador referred me to his wife was a gesture of love and care. Altea was able to take care of me and, at the same time, to set limits, to point out my truths despite my anger, and help me find a way to see my difficulties without my usual harsh judgments. She also treated me as a unique being and put all her intelligence and empathy at my disposal.

I have managed to understand many things from my childhood that affected how I related to people. As a child, the vivid fantasies about my family being extraterrestrial responded to the radical strangeness I felt in my own home. The abuses I suffered led me to split up when my mother exposed me to my drunken father and his uncontrollable sexual appetite and tyranny. On one side, there was my body, without agency. On the other hand, I sought shelter in my thoughts and fantasies for enduring the moment, avoiding any sensation or feeling at all costs. I still remember my father's authoritarianism and my mother's submission. "Be careful with your dad. He gets angry" was her permanent warning to my brother and me, to keep my father happy.

My parents used to repress my intense emotionality, so, at a given time, my emotions imploded or exploded, and I became hypomanic or depressive. Anguish and paranoia used to come. I entered states of unreality where I came to exist outside of my body. I remember seeing my face warp when I looked in the mirror. My body in the mirror was a total stranger to me. It seemed unreal and empty.

Little by little, I recognized myself and accepted that I could do things well, so life began to be pleasant. I stopped purging and injuring myself. I started to enjoy food and connect my body to myself. I got a job at a university where I feel I have made important contributions. I also met Amadeo, the most generous man anyone can imagine. We have been together for seven years. Paradoxically, I was

ready to bond when I was able to share my whole vulnerability. My emotions no longer invade me, nor do they become crushing demons that overwhelm my existence. Psychoanalysis has been a place of acceptance where I have learned that difference can be enjoyable, even amazing. I must admit that my life is not perfect, but I can already tolerate imperfection and even laugh about it. Amadeo has taught me to play and to laugh a lot, even at myself.

Doctor Altea and Amadeo cleansed my soul through their love and patience, as in Isle of Dogs. That session was a breakthrough; I saw how to unravel my emotions. Now, when I go to sleep, I try to describe what I have felt at any given moment of my life. I focus on the sensation and gradually realize that it transforms into an emotion. Disgust, for instance, makes me curious because of its expelling nature of the strange. That definition fits into what I used to do by purging or hurting myself during my experiences as a stranger, an alien, and even an otherness. That led me to destruction once, but I have understood that one can come to love and care for what one sees as a monster at first. Awe, in contrast, is inclusive and loving. So now, I try to understand disgust and turn it into wonder. The universe doesn't give or take away. It is each of us who can build or destroy. We can choose to be amazed and amused, or reject and expel.

Currently, I am doing a doctorate. My dissertation seeks to explore emotions in the aesthetic experience of bioart. I have understood that deep down, that dissertation is about taking care of my own difference through the exploration of the otherness materialized in bioart works, but that's another story.

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## My Journey from Psychological Rape to Spiritual Awakening

Fehmida Visnegarwala

India

y medical history is what most psychiatrists may elicit as "typical." I was born as a fourth sibling in an average middle-class, extra-conservative Muslim family in India. Growing up in the midst of unspeakable, truly unspeakable sexual and physical abuse is a childhood history that for patients with mental illness is quite stereotypical, right? Add to that my family history of mental illness, which makes my story even more juicy and typical.

But what I would like to narrate is something much beyond a case history of Bipolar. I want to give you a glimpse of my experience as Bipolar as my spiritual awakening.

I always had a lot of energy as a child and young adult. While growing up, I passionately wanted to be an 'astronaut' while watching the stars and planets from my bedroom window.

I did not reach the stars but did reach the treetop! At the age of 40, by all worldly standards, I was successful! I was a tenured faculty at a premier medical college in the USA. I saw patients, did clinical research in HIV medicine, published in peer-reviewed journals, was invited for talks as a well-known and well-respected physician-educator and researcher with national and international standing. I had married a Hindu man I loved very dearly and had two beautiful children who did well in school. So love, money, power, and an enviable social standing, were all within my reach, or at least so it seemed.

In 2004, this perfect picture was shattered into a million pieces.

The misdemeanor of two guys who worked for me, wherein they manipulated and helped forge signatures on more than three hundred research subjects' consent forms, leading to a six-month-long research enquiry, wherein all aspects of my life were judged, including my role as a researcher, doctor, wife, mother, and even human being. I was made the scapegoat for inter-institutional rivalry and corporate politics of three very powerful institutions. During the final two months of the investigation, I was stalked by innumerable people. It left me completely naked and vulnerable. The trauma of this investigation was so significant that it felt like a psychological rape. I felt I had been raped thousands of times. I had contemplated killing myself several times during this time.

Everything I knew to be true: my work, my marriage, my status in society, and my strength of mind, were all sucked into this black hole.

I had a psychotic breakdown and required hospitalization. Even though I was completely exonerated after the investigation, instead of continuing my work as an academic physician, I was suddenly seeing psychiatrists and lawyers.

After that, I had two more episodes of 'break downs,' with severe palpitations, and sweating and intrusive thoughts. I was diagnosed with severe post-traumatic stress disorder (PTSD).

I also went through a devastating divorce, which at that time left me with no home, no work, and no marriage. I could no longer live in the same city, so with the goodwill, kind and thoughtful support of caring and steadfast friends and a sister, I moved with my two children to another city. That was when I was diagnosed with Bipolar disorder.

I had my highs but not many lows. During one such period of depression, after an intense death experience of someone close to me, I took an overdose. I was in a coma for five days. My surviving and thriving through it is nothing short of a miracle!

The trauma at work caused a complete melt-down of my ego as an accomplished physician and a career woman. It was my 'Ego Death' of sorts. Thus I was ready spiritually when I met my 'spiritual master.' They say when you deepen your yearning, your master will find you. So it was with me.

I met 'Sadhguru' in 2006. Within his *Inner Engineering Program*, I was initiated into an ancient meditation practice called Shamabhavi Maha Mudra Kriya Yoga, which has transformed my life in the most beautiful way. When I was first initiated, I felt a beautiful yet bewildering 'dancing' sensation in my

abdomen. I felt pregnant with something moving in my belly rhythmically. This was the same sensation I had during my earlier 'psychological breakdowns.' This made me certain that the so-called psychological breakdowns were also definitely spiritual in nature. My many spiritual experiences in the past 16 years have confirmed this for me.

I would like to describe one particular experience: I had sustained a severe knee injury during dancing. I had all the signs and symptoms of inflammation: rubor, dolor, tumor, and loss of function. I had an appointment with an orthopedist the next day. But the previous evening, I was doing the meditation practice, and suddenly with an electrifying sensation, all the signs and symptoms of inflammation were gone within seconds! Of course, because of my training as a physician, I was absolutely astounded by this phenomenon. At the same time, it endorsed the belief within me that the "creator is within you!" If you can access the creator's energies, you can be healed! I completely believed that if physical pain can be healed, so can mental traumas. Over the years, this conviction has allowed me to stay afloat despite all my life's ups and downs. From being an agnostic for twenty years, I was now a firm believer in the Divine!

Over the years I have experienced Kundalini awakening with a Kundalini rash down my spine, out-of-body experience, bliss, and ecstasy, which have all been very profound and real.

I was a single parent, worked in private practice in HIV medicine, was involved in research, and at the same time pursued a degree in public health. Thus I was doing well socio-occupationally on a modest dose of a mood stabilizer.

The modern psychiatry literature abounds with the association between religiosity/spirituality and mental illness, particularly in Bipolar Disorder. However, religiosity/spirituality is considered a 'symptom' of illness, but not as an experience of transcendence. This is my fight against modern psychiatry. At the expense of being considered confrontationist, I say that most mental health care providers have never experienced these states of high and therefore blithely and ignorantly pathogenise them. Since the DSM lists almost every experience

as abnormal, people blessed with these experiences are "named and judged as mentally ill." This is often regardless of all evidence to the contrary, without allowing for other expressions or explanations as have now been put forth by the new and emerging field of "transpersonal psychology."

I've had nine episodes of so-called mania in the last fifteen years, lasting from a week to twenty weeks, mostly without medication compliance, most requiring hospitalizations and rehabilitation. Each time, whether I hit rock bottom socio-occupationally or not, I have always gained spiritually and have experienced states of bliss, joy, and creativity that have enabled me to rally and learn to re-invent myself and go forth.

I have been frightened, ridiculed, humiliated, coerced, victimized, abandoned, exploited, and made to feel invisible because of my mental illness. People think they can do whatever they want with us as we—the mentally ill—are somehow less-than, abnormal, or stupid. Our opinions do not matter, even when talking about mental illness. We are often thrown into benumbing isolation. Despite all that, I have learnt to forgive, and I am peaceful, joyful, and grateful within me most of the time.

The trauma that I experienced completely melted my ego and shattered my personality. It was like a flood that came into my life and washed away everything I didn't need to reach this 'new kind of success' and left me bare and naked, just the way the Divine wanted me to be. I know I could have spent another twenty to thirty years doing the same things as building a great profile as a doctor and researcher, but never having experienced life the way I have. I would have never touched ecstasy and joy the way I have with my so-called 'manic' states.

I have realized that society judges very narrowly and is basically wrong. I have learnt not to allow myself to be judged by society's standards. The states of ecstasy and bliss during my manic states are only momentary, yet they are transformative. They fill me with a conviction that one is much bigger than just a body and mind. One is part of universal consciousness that is sublime, beautiful, pure, all-encompassing, unconditional love! You

will appreciate that I am unspeakably grateful for having tasted a smidgen of this Divinity within me.

I would like to reproduce this poem that I wrote at the height of my madness in 2016.

#### What you call as Madness

What you call as madness Is my taste of the Divine What you call as madness Is my affair with the Divine

My madness cracks my mind Enough to peek through the mirror To the other side of the blind To feel myself as pounding work of the creator

> To feel the flowers, To feel the air, To feel the leaves, To feel the moth's wings Dance within my heart

I'd rather be mad today Than be sane If it allows me To experience life this way every day.

I am currently on a minimal dose of medication that does benumb me and makes me somnolent and forgetful, yet I am functional without relapse of my mania for the last three and half years.

I practice yoga and meditation every day, which keeps me in touch with my Guru and the source of creation while keeping me grounded and real.

I am absolutely grateful for the unflinching support and love I have received from my family and close friends. It is extremely important to have this support in day-to-day living and to endorse your deepest beliefs during your so-called psychosis. Talking freely about the so-called "delusions" is enormously healing and leads to mutual growth and bonding. I am extremely fortunate that I have five such people in my life who keep me substantiated and safe. I both celebrate and lament my everyday trials and tribulations with these few people who stand as a rock in my life.

Through my spiritual experiences, I have learned that my body is my 'temple' and keeping the 'gut microbiota'—the gut-brain axis intact, is of paramount importance. I do everything to maintain my gut-microbiome, including a balanced diet, taking turmeric, neem, and Spirulina (as a pre-biotic).

Through my so-called madness, I have realized that the academic game is phony and that the reality is far deeper and more complex than the reductionism of science offered me to believe. It is obvious that the literacy of consciousness is very different from medical literacy. This knowledge and perception have offered me a much deeper insight as a physician and public health professional where I treat the mind, body, and spirit as a continuum. Today, I don't do even a fraction of the work that I did as an academic physician, but it's not how much I do that matters, but how well I do it.

At work, I make sure that I only take up things that I can handle without being overwhelmed and without any negativity that could bring back any flashbacks of the devastating investigation of 2004. It's the small things that matter and give the pleasures and satisfaction of life.

Everything that happens during periods of mania is trying to teach me something significant about life! For instance, the importance of waste management, energy conservation, and the importance of gut-microbiome as a living legacy of earth within us! These are all deep and profound realizations that are extremely transformative. During the so-called manic periods, one is vibrating at a different Divine frequency. It feels like being controlled by a 'Divine alien force.'

Thus my appeal to the caregivers of Bipolar persons is not to ignore and pathogenize the thoughts and actions during this time, but to learn to respect them, for the Crazy are also Wise! It is with an acute awareness that I do not mean to romanticize 'madness,' but to give it its due respect.

I have run short and outrageous spiritual sprints with each of my many episodes of mania. The spiritual highs with the mania are very addictive. However, by taking complete responsibility for my psychological and spiritual well-being, I want to run a marathon by remaining stable without manic breakdowns for a long time. My identity as a human being is much beyond that of just being Bipolar and mentally ill. I know I have been awakened to this

spiritual path of complete healing, however tortuous or obscure it may seem.

3

## On the Road to Get Our Son Cured From **Schizophrenia**

Luc De Bry (father), Catherine De Bry-Meeùs (mother) & Valère De Bry (son)

#### Belgium

ur family lives in Belgium. We have two girls followed by two boys. In May 2012, on his 20th birthday, our first son was diagnosed and stigmatised as "schizophrenic." To make matters worse, we were left with no hope, the psychiatrist added: "(1) it is incurable, which means disability for life; and (2) to survive, his use of psychiatric drugs, for life, is required . . . "

Because psychiatrists assume that schizophrenia is a genetic disease, stigmatisation affected our whole family. Our children became afraid that they will not find the love of their lives: "who would take the risk to have a schizophrenic child?" Since then, we have met many families traumatised in the same way.

Being a research scientist with a PhD in biochemistry and genetics, I learned: "Who searches, finds!" So, I started to do my own research, exploring the psychiatric literature. That proved to be a rather depressing experience. For instance:

- No psychiatrist-researcher is looking for a cure . . .
- Due to a huge conflict of interests with the pharmaceutical industry, plagued by corrupted and bad science, the psychiatric literature is characterised by "cherry-picking results," "misinterpreted results," and "unsupported conclusions."
- The probability of suffering from any genetic defect is less than one in a million. But, instead of being equal to that, the probability of suffering from schizophrenia is near 1% (i.e., 10,000 times more). Therefore, a genetic hypothesis is invalid. There are other causes than genetics, most notably cumulative traumas.

· Apart from a few exceptions, not looking for causes, psychiatrists look only at symptoms. Then, they prescribe psych-drugs for "stabilising" patients. Stabilisation falls against the Second Law of Thermodynamics, which states: "everything evolves towards entropy, higher chaos." Battles against any illness are chaotic indeed.

After 12 months in psychiatry, with his prescribed high doses of 4 different psych-drugs, our son was so "stabilised" that he had to sleep around 18 hours per day. At 21, he could no longer function properly, could no longer practice any sports, could no longer study, could no longer go out with boys and girls, and could no longer enjoy his youth and Saturday night fevers. He had gained 45 pounds. Dozed off all the time by the psych-drugs, he often fell on the stairs, risking breaking his neck. His saliva drooled uncontrollably from his mouth—an unpleasant effect of clozapine. In the morning, with his pillow completely wet, he woke up bathing in his saliva. In addition, because clozapine endangers immunity, he had to undergo a monthly blood test. He was sicker from the high doses and long-term takes of prescribed toxic psych-drugs than from schizophrenia. Seeing him so miserable increased my determination to find a cure.

In May 2013, after a year of disappointments following scientific research rules, I did my U-turn: turning my back on professionals, I started to research in the direction of diagnosed people.

They do not publish in academic journals, but they do publish a lot. To explore their valuable literature, which is even peer-reviewed, to unveil hundreds of "reproducible" success stories astonished me: with respect to curing mental illnesses, shifting the paradigm, sufferers who managed to heal are the true experts, indeed.

At first, it all looked too good to be true. By synchronicity of life, I had taken a week off work to do our yearly house maintenance. Not willing to share false hopes with our family, I used it for investigating deeper: among therapies, "Open Dialogue" is well reported in the academic literature. By Friday, I was convinced: here is how to get our son cured.

End of the afternoon, back from work, my wife entered our house, slamming the doors. I took an "Open Dialogue" report, and we met in our kitchen. She was furious: "you took a week off to maintain our house and you did nothing. I hope that you have a good excuse!" I passed her the report: "Please, Darling, look!" She started to read..., tears came to her eyes, her legs started to wobble. Before she fell, I managed to sit her down on our sofa. She kept reading. As it had happened to me the week before, the more she was reading, the more she was crying: in her mother's heart, hope was back too.

We fetched our son at the psych-ward to spend the weekend with us. We passed him the report. Numbed by the high doses of prescribed psychdrugs, he could not express his emotions, but he was very much interested. I showed him and my wife many reprints plus 4 documentaries on DVD, 01h15 each by Daniel Mackler. After dinner, we watched "Take These Broken Wings," a film about professionals helping sufferers to get cured and two ex-sufferers, Joanne Greenberg and Catherine Penney, who are cured. By the end, realizing that curing schizophrenia is possible, we were excited.

On Saturday evening, we watched "Open Dialogue," filmed in North Finland, full of interactions with members of the "Open Dialogue" Team. As stated by Robert Whitaker in his 2010 book "Anatomy of an Epidemics," we understood the following:

"In Western Lapland [ . . . ] their conception of psychosis is quite distinct, as it does not really fit into the biological, psychological, or psychiatric category. Instead, they believe that psychosis arises from severely frayed social relationships. Psychosis does not live in the head. It lives in the in-between family members and the in-between people. It is in the relationship, and the one who is psychotic makes its bad state visible. He or she "wears the symptoms" and has the burden to carry them."

When that second film ended, with more tears of hope in her eyes, my wife turned to me and said: "Darling, to learn more, you must go meet that fabulous Team, learn directly from them and take our son with you!" Our son confirmed: "Yes, Dad, please let's go!"

By another synchronicity of life, a month later, there was a three days "Open Dialogue" workshop

organised at Hämeenlinna, 115 km north of Helsinki, Finland. Hence, on Sunday, we planned our travel. In the evening, following his health insurance rules, I brought our son back to the psychward. He was exhausted. A bit later, fearing that it may be too good to be true, he texted me: "Dad, do you really think that I have a chance to get cured?" I reassured him: "Dear Valère, I do believe in this innovation, and I promise you that you will get cured and get your life back!" He added: "Thanks Dad, now I can sleep!" I cried.

Three weeks later, father and son, we landed 2,000 km away from home at the airport of Kemi-Tornio. We drove directly to Keropudas, the 170 beds psychiatric hospital. We saw two long buildings. The one on our left was clearly empty. The one in front of us was three-quarters empty and lighted for one quarter, where the administration works.

Impressed, we entered that building. Professionals of the "Open Dialogue Team" were all out, working at family homes. Sometime later, a nurse of the team came in. He confirmed the published results and their selective use of psych-drugs: 83% of their patients do not get any prescription for antipsychotic drugs. Within five years, 80-85% of the patients are cured and in full-time studies or jobs. Good for local taxpayers, costs are more than 20 times lower than the psychiatry as practised out of Western Lapland.

The next morning, his pill-organizer empty, our son realised that he had forgotten his boxes of psych-drugs in Belgium. To go cold-turkey in Lapland was not our plan. My wife emailed us a scan of his prescriptions. We have been to eight pharmacies of Tornio. Worrying for us, the eight pharmacists said: "Sorry, we do not have these medications!"

Suddenly, it stuck our eyes out: in Western Lapland, they found a cure for psychosis, which emptied their psychiatric hospital, toxic psychdrugs are no longer on their local market, and they saved tax-payers money. Happy by this evidence of the "Open Dialogue" success, we decided to go to Sweden, where they still have traditional psychiatry. We found the four psych-drugs.

A day later, we arrived at the workshop place. There were 310 participants from 7 different countries. We met the project leader of the "Open Dialogue" development, Prof. Jaakko Seikkula. We learned that the "Open Dialogue Therapy" has roots in the approaches of Ronald D. Laing, Mikhail Bakhtin, Tom Andersen, etc, and in family therapy.

Organizers had invited a theatre troop from London, UK, to play the role of a family during demos. Inspired by the remarkable "Open Dialogue" results, that troop published a book entitled "The Eradication of Schizophrenia in Western Lapland." They presented their play in London in 2014.

Once back home, we decided to take our son out of psychiatry and risk our own trials and errors to help cure him. On our learning curve, we discovered ten golden rules:

- 1. The best medicine is unconditional Love!
- 2. No healing therapy is perfect, but by combining healing therapies developed respectively for anorexia, bulimia, psychosis, schizophrenia, bipolarity, autism and ADHD, we got to near-perfection.
- 3. Instead of a stressful clinical environment, for healing, a natural environment is a must. Methods and results obtained in natural environments credited to Karl von Frisch, Konrad Lorenz and Nikolaas Tinbergen in their 1973 Nobel Price for Physiology and Medicine. They are helpful for optimising healing therapies.
- 4. Nutritherapy must complement psychotherapy: an adequately fed body enhances healing efficiency.
- 5. By cross-fertilising therapies, the "Open Dialogue" of Jaakko Seikkula and Birgitta Alakare, the "Living with Voices" of Marius Romme and Sandra Escher, the "Healing Homes" of Carina Håkansson, the "Secret Language" of Peggy Claude-Pierre and the "AutismOne" of Marcia Hinds, we realised that, due to their cumulative traumas, so-called mentally ills are suffering from a powerful negative mind, constantly devaluing them, which drives them mad. A 3 year old patient of Peggy Claude-Pierre called it "the monster under my hair." Therefore, a major task of healing therapists is to help sufferers revalue themselves until their negative mind is gone. Once the monster, the cause of madness, is out of their head, they are cured. As highlighted by Norman Doidge, in terms of neuroplasticity, healing therapies contribute to the rewiring and reprogramming of the brain.
- 6. A team to accompany sufferers on their healing road is required: they cannot do it alone. With the current psychiatric dogma of incurability,

- building a team with members who believe that, with a humanistic and holistic approach, curing mental illnesses is possible, is the most difficult of all.
- 7. To express their true personality and to interact naturally with their therapists, families and friends, sufferers must be psych-drugs-free. Their supporting team must be in place before starting to taper, because adequate psychotherapy replacing psych-drugs prevents relapses.
- 8. The healing road is chaotic: acute sufferings, hallucinations and delusions, which are metaphors, plus anger, which is a way to grieve, are absolute and temporary necessities for healing. Curing therapists respect them.
- 9. Our family accountancy confirms: to apply healing therapies, not reimbursed by National Health Insurances as yet, in Soteria-like therapeutic communities, in healing homes or in family homes, is 15 to 30 times cheaper than psychiatry.
- 10. Don't worry, once cured, stigmatisation vanishes by itself.

After safe peer-guided weaning, our son is now psych-drugs-free for four years. No relapse. He lost his extra-weight and resumed sports. Courageously, he keeps progressing. We are proud of him.

We are now raising awareness, organising short courses, and assembling a critical mass of concerned families and professionals with the view to get Governments to pass laws for investing our taxes into high-quality healing therapies for all mental illnesses.

Closing our story, we are very grateful to ex-sufferers and healing therapists, many of whom we met in person, for their teaching and support.



#### The Lost Darn Tea-Time of the Soul

Nataliya Yaneva

Bulgaria

'y name is Nataliya and I recently turned 32. I'm from Bulgaria. And I have social anxiety and high-functioning depression.

This is my story of how I experience both conditions and how I try to somehow manage them.

Social phobia I've had since my early childhood. When I look back, there is no time in my life when I haven't felt deeply shy to the point that I get stupefied in some social situations. Shyness is what I thought it was back then, and I fervently hoped I would shrug it off one day when I got older, more mature. Living in a post-socialist country didn't make things better since information on, and understanding of, mental health is not something Eastern Europeans are particularly well known for. In fact, mental health is still quite wretchedly understood, and if you are visiting a psychiatrist in Bulgaria, that means there's no better explanation than you're a nutter. Yes, even the language most people use here is not flattering.

I was never good at making friends. Throughout my school days, I've had two or three good friends but I could never manage more than one at a time. I never went out to parties or other social gatherings. All I could do is go out with my one friend and have a one-on-one conversation. Anything with more people perplexed me profoundly. In some ways, it still does, 17-odd years later. Actually, I don't remember much of my time at school, except that I feared every day like hell because it included random interactions with other students, teachers, and people on the bus. I felt best during holidays when I got to stay at home and shunned meeting people altogether.

Since I mentioned home, I might as well share how my family relations used to be and still are to this day. I love my father deeply, and he taught me a lot, but he was never one for a personal problemrelated conversation. I remember sharing with him that I had trouble interacting with people, but he rather took it as something that will resolve itself and didn't deserve much thought—that I was just a bit shy. It's not that he didn't care, but as I mentioned, information on such topics was really scarce then. My mother, on the other side, is a typical example of an emotionally absent parent. Our relationship has always been cold at best. To this day, I cannot remember having a single meaningful conversation with her or having received a piece of wisdom I could use in life. I had terrible quarrels with her when I was living at home. She is the type of person that wouldn't even remotely understand if I was to share about my 'shyness,' let alone help me in some way, so I never did. I rarely ever keep in touch with my four still living grandparents, except for one of my grandmothers, who is also a deeply troubled and anxious person. I guess I took after her in a way.

I couldn't say things didn't get a bit better with time. They did. I went to university, lived in another town, met my first boyfriend, who later became my fiancé. All this time, I continued having trouble connecting with people and realized it was something different from shyness that I had. It was something deeper and, to my mind, darker. I began digging for answers, and I found some. I started sharing my newfound secret with my fiancé slowly since I was very ashamed of it. But I needn't be-I only found understanding and even more love. That made me feel slightly better about myself, and I reached for help. I started visiting a psychotherapist. It only lasted for a few months since we had (still have) financial struggles. I'm glad for my sessions though, since I've learned some things about myself.

Despite the fact that I have fought my social anxiety for most of my childhood and for my entire adulthood, I still face many challenges despite the pills I'm currently taking for my condition. I've missed so many things throughout my life due to my anxiety. I've missed opportunities to make friends, to go abroad, to get a nicer job. After graduating from university, I briefly worked in an office, but I couldn't handle it well, so now I work from home. I studied law, by the way. I know the irony of it. You should really be an affirmative and socially skilled person to be a lawyer.

My heart still races when I have to do something new—from submitting documents to a random institution to speaking on the phone with strangers. Phone conversations are still nightmares. I always rehearse what I need to say in my head before the call and try to recite it as quickly as possible when I find my bearings and actually make the call, sometimes interrupting the person on the other side of the line in the process. I always go to an empty room to make a call, because I'm too embarrassed if someone listens to me. When I need to go out of the apartment, I make sure there aren't any neighbors in the hallway and only then do I proceed. When I

walk the streets or do whatever in public, I always feel like everybody is looking at me and waiting for me to make a mistake so they can laugh at me. I fear being judged and ridiculed. I have trouble speaking to authority figures, which to my mind, is pretty much everyone. I know all this is just in my head, but to me, it feels quite real. My social phobia gives me a million other quirks, and I cannot imagine a life without them, pills or no pills.

But let me share about my other condition so you can have the full picture.

Several years ago, I decided to change career paths. I've come to the conclusion that I won't make it as a lawyer after all. I was disillusioned with law anyway. So I enrolled at university again, this time picking translation studies as they reflected my disposition and abilities better. I continued supporting myself financially while studying. At one point, I was visiting lectures in another town, translating a book for a publishing house, working as a freelance translator for various agencies and individual clients and transcribing 1,500 pages worth of drama lectures for a university professor as a side gig. I had a rigorous schedule I had to stick to very closely if I wanted to make it. So I graduated from university with honors, translated that book (and a few others down the line) and transcribed those lectures, but the price I paid was ghastly.

After my merry-go-round of engagements was over, I was physically and mentally devastated. I was burned out but didn't know it then. I remember one day lying on the sofa, staring at the ceiling and thinking I preferred if I didn't exist—nothing as dramatically tinged as being dead. I just didn't know how to keep doing whatever it is that people are doing in life. I was utterly drained and life was completely devoid of stimuli for me to continue with it. It was like I was stunned. That continued for several months as far as I can say. I really wasn't up to the challenge of keeping track of time back then.

I thought I was just very tired. However, things didn't get better with time. They transmuted into something else. I felt profound emptiness inside, an abyss of meaninglessness. I thought I would never feel normal again. Things that used to give me pleasure were mere burdens, something I should go through in order to make it to the end of the day and go to sleep. Sleep was my salvation. I didn't

have to feel or think or be confused then. In a way, sometimes sleep is still my salvation today, some years later. I yearned to get over everything I didbe it work, reading a chapter of a book, or watching a movie. I felt restless, useless, and pathetic. I was afraid to share all that with anybody because I was ashamed again, as with my social anxiety. I felt half of a person, not a worthy human being to get myself into this state and persist there.

I finally shared how I felt with my fiancé, who is my soulmate and my best friend. It happened gradually, over the course of many conversations. There was crying. A lot of it. I couldn't find the words to express what was inside me, this murky pool of nothingness. I remember saying 'I don't know' a lot. I truly didn't know what was going on with me and that scared me out of my wits. I was frightened of what my brain was capable of. I still am. Again, I found understanding, readiness to be listened to and loved. Years later, I tried to share my condition with my father, but he wasn't able to understand me. 'Depression' is not a word in his dictionary. I was angry at first. Then I realized that times were different and problems were different when he was younger. Mental health was just not something you spoke about. So it didn't exist of sorts. I also tried to confide in a friend of mine. She practically never asked me again how I felt. I used to be on mild antidepressants for a year and felt somewhat different but it was not enough. So I stopped taking them.

Despite all the struggles I've been through, I'm grateful for love. That makes me want to keep going. A few months ago, I started taking another kind of antidepressant. My social anxiety and depression symptoms are somehow milder, although they are still here. I try to cope as best as I can. I started driving lessons—something I've dreaded since I was 18 because I cannot do anything right if someone watches me. It's going alright so far. I've also started learning French and applied for traineeships at different EU institutions. If I make it for a traineeship, this would be one of my biggest thrills and certainly my greatest trial. I dream of living and working abroad, navigating my way in a foreign environment, and proving to myself that I can do it. Life's been quite hard the past few years, especially since I became the sole provider for my fiancé and me three years ago. But I'm not ready to quit believing things can go better.

Having depression is a peculiar experience. I wouldn't go so far as to say I'm grateful for it but I certainly learned a great deal from living with it. I've read a good amount of books on anxiety and depression and understood aspects of myself that were deeply hidden. I found out that many other minds—great and ordinary—also search for their ways of living with depression and discover some truths in life-despite of it or because of it. I've learned to be more tolerant, more patient, more compassionate, and thoughtful. I wouldn't be the person I am today without my anxiety and my depression. In a way, I've come to terms with the fact that they may never completely leave my side, because as far as I know, the one is a peculiarity of mind and the other may be a lifelong companion and relapse once triggered. My 'black dog' as Churchill called his depression. But, you know, it's sort of fascinating, too. To have this strange and intensive relationship with your own mind and to discover its layers over time. The most beautiful thing I've read about depression is from the book 'The Noonday Demon: An Atlas of Depression' by Andrew Solomon, and I'll finish my story with it:

'Every day, I choose, sometimes gamely and sometimes against the moment's reason, to be alive. Is that not a rare joy?'

6

# **Living to Die: On Chronic Suicidality and the Authentic Self**

Michael Nair-Collins

United States of America

#### Introduction

few months ago, I walked into my room and saw one of my belts lying on the floor. It was a D-ring belt, the kind that comes with cargo shorts, and it makes a natural noose. Seeing the belt, I placed it around my neck and

tightened it. I walked to the metal clothing rod in my closet, prepared to tie the other end of the belt to the rod, drop to my knees, lean forward, and die—just as I had rehearsed. A thought occurred to me, very matter-of-factly: "well, this is it. This is the end." That simple thought was enough to shake me out of the reverie I didn't know I was in; out of the depersonalization I wasn't aware of. I was still deeply suicidal and still profoundly depressed, but more aware of myself and my surroundings. I removed the noose from my neck, laid on my bed, and wept in agony and intolerable psychic pain.

I have struggled with suicidality for years and perseverate on suicide regularly; I have cut and burned myself more often than I can recall. But this time something was different, that in retrospect I find especially frightening: there was no hesitation, or thought, or time, intervening between the stimulus of seeing the belt, and the behavior of placing it around my neck, fully intending to kill myself. It was almost as if I was watching myself as I went about the business of ending my life. Thankfully, the interrupting thought "woke me up"—if that is the right phrase—just in time to make my decision with greater clarity. I want to die; but not today.

Living with chronic suicidality, in the context of bipolar disorder with its characteristically dramatic changes in mood, energy levels, thought patterns, emotions, and behaviors, can be deeply confusing and disorienting. In particular, my understanding of my own authenticity, my true self, literally who I am, sometimes feels ephemeral, ungrounded, nebulous. This is particularly the case as I emerge from a crisis period, wondering—with no small amount of fear—why is my brain trying to kill me?

In this narrative, I explore the concept of the self, more specifically, of *my*self, set within the background of living with bipolar disorder. Along the way, I will share parts of my story in the hope that, if others read this and feel similar experiences, they will know they are not alone, and perhaps even may find some comfort in this knowledge.

#### The Allure of Death

I have manic-depression, more commonly (though in my mind, less accurately) known today as bipolar disorder. I've had it since my teens, and so the profound changes in mood, energy, and thought patterns have simply been a part of my life since my formative years and throughout my adulthood. In my case, I have experienced all the variations of mood episodes: the severe depression, where all hope is lost, all energy drained, and something like existential fatigue takes over. I am simply tired. Tired of everything, and especially, tired of living. But in this state, there is such fatigue and avolition that very few thoughts enter my mind. It is just a state of intense sadness, emptiness, hopelessness.

On the other hand, the pure, euphoric manias tend to characterize the condition earlier on and become less common later. Some of my first clearly definable mood episodes that I can recall were states of pure euphoria, highly energized and productive, exceptionally sociable, less sleep needed, coupled with a range of exceedingly dangerous behaviors, often resulting in serious injury such as broken bones.

And then there is mixed mania, a combination of both "poles": The emptiness, sadness, and psychic pain of depression, combined with agitation, anxiety, restlessness, impulsivity, and often intense anger. It is difficult to describe this condition to someone who has not experienced it. It is contradictory, disorienting, frightening, and wondrous. There is a horrible nothingness, darkness, and pain; an agitated, despairing violence in my soul, yearning for self-annihilation; yet at the same time, I experience profound, even transcendent beauty and meaning in suffering.

Over the last several years, my suicidal ideation has grown more intense and overwhelming, with suicide experienced as seemingly inevitable. I see suicide as a spiritual and aesthetic accomplishment; a Good Death, one to be desired and admired. I've come to see death by one's own hand as the ultimate affirmation of life and existence by fully grasping, and acting on, the only true existential choice. In tandem with its aesthetic and personal value in perfectly embodying autonomy, suicide paradoxically reveals itself as the only possible manifestation and expression of the soul-searing despair and intolerable psychic anguish that one's own mind creates to destroy itself. And so the suicidal mind, or at

least mine, embraces contradiction: meaning from meaninglessness; efficacy from futility; affirmation of life through self-enacted death.

#### The Authentic Self

I am here writing this, and so of course the allure of death is not the only aspect of who I am or how I think. Indeed, I don't spend most of my life in a suicidal crisis. And I want to live, at least for now. I am more than an isolated, atomic "self" made up of only my internal memories and experiences. My identity is also social and relational. Who I am is partly defined by relationships to other people, especially to my friends and loved ones, and so the effect of my suicide on them must be included in my aesthetic musings on a good death. Since who I am is partly defined relationally, my death is also partly defined by the severing of those relations, and how death severs them can have tremendously different impacts on those left behind.

When confronted with this truth, I must accept the reality that no matter how beautiful it may seem to me, no matter how spiritual and glorious, no one (or very few) will see it as I do, instead seeing it as a horrible tragedy (though I would disagree). I might have my superlative achievement, but I will leave my family and friends to go on living without me, carrying the grief and loss, the pain, the lack of understanding, perhaps guilt. Even though it may be unfair that the living and the non-suicidal cannot understand the power and beauty of suicide as I understand it, the fact remains that they won't see it as I do. This aspect of suicide has, in the past, given me enough space to take the first, critical step back from that terrible brink. But I also know that is not enough in the long term—one cannot live solely out of obligation to others.

However, slowly clawing and scratching one's one way back from that tenuous place at the edge of life and death can be revealing. Looking back, I feel afraid, seeing how close I have come. Why would I feel afraid, if not that there is a part of me that is not ready to cast off this mortal coil? There is indeed a part of me that wants to live. My life is valuable. I care for those close to me; I find meaning in my work, in my teaching, in my projects in life.

And indeed, the powerful experiences I undergo, they too are valuable. I experience great beauty in suffering, and a profound grasp of meaning from meaninglessness.

But how do I make sense of this? Presumably I am a single self, a (seemingly) unified individual. And yet, I have deeply contradictory urges and desires, conflicting emotions, shifting cognitive frameworks. Indeed, wanting to kill myself and wanting not to kill myself are contradictory desires. Am I a fractured self?

The standard explanation is to medicalize me, to disorder me. I have an organic brain disorder, a function of genetic susceptibility combined with trauma at a young age, which manifests in the experiences and behaviors described above. The core idea is that when I experience "symptoms," this is not me. It is my disease. An otherwise very helpful book on living with bipolar even features a table with columns labeled "self" vs. "symptoms," so presumably, I could go to this book and discover my true self, and discard those aspects that are my symptoms, not me. "You are not your illness" is a common refrain in mental health circles, and I don't buy it.

I don't deny that my brain and emotional, cognitive, and behavioral functioning appears different from many others, nor that these differences have caused me severe difficulties in life. But the only conclusion I take from this is that I am neuroatypical: my brain/mind is not "typical" (whatever that means). But the fact of my neuroatypicality does not imply that I must accept the disorder model for explaining my authentic self, a model that denies the richness of my experience, including all the pain and all the joy, as genuinely *mine*, as authentic aspects of myself. The disorder model shrugs off these experiences as pathological, to be gotten rid of or "managed." This framework sees much of my life's experience as nothing but "dysfunctional biochemical activities" and not my authentic self. I reject this idea thoroughly and completely. It is a common exercise to retreat to the reductive "biochemical changes" trope when we wish to pathologize. When we don't, we describe other experiences and behaviors straightforwardly as aspects of the authentic self. All my experiences are a function

of biochemical activities, and *all* my experiences are mine, experienced by my authentic self. They are not to be placed in little boxes of "self" versus "symptoms," selectively dismissing and pathologizing most of my life's experience as "illness" while reifying and placing society's imprimatur on the remaining "normal" experiences.

If I refuse to be medicalized, how do I make sense of the contradictory desires and shifting cognitive frameworks? Must I accept that I am a fractured self, or that I embody fractured, incoherent agency? I don't think so, and there are two concepts that are useful in understanding my authentic self: Perspective, and dialectic.

All of us experience the world, and ourselves, from a particular perspective. There is no "god's eye" point of view, seeing all things from all perspectives; or from no perspective at all. This is important because it shows that two statements may seem contradictory when in fact they are not: I might see an object, say a wooden box, and say it is black while, looking at the same object, you say it is red. They can both be true because there is always an unstated background assumption: From my perspective, the box appears black and from your perspective, the box appears red. Our experiences both accurately reflect the color of the box, but neither accurately reflects the entire box's color, since it is painted black on one side and red on the other. This simple example helps to illuminate how perspective can explain my apparently contradictory desires and beliefs.

When I am actively depressed, especially in the form of mixed mania, I see the world and my place in it from a very different perspective than when I am more "stable." The scope of my perspective in the two thought patterns are so vastly different that what seems a reasonable response to the human condition, to *my* human condition, are themselves vastly different. From one perspective I am looking at the human condition in view of the universe, the infinity of time and space, and the meaninglessness of existence, coupled with overwhelming, beautiful agony. It is a spiritual and existential perspective, concerned with ultimate reality, meaning, and purpose. It is the perspective of the profound. From

this perspective, thoughts of finding meaning and affirmation of life through self-enacted death make perfect sense. And it is from this perspective that suicide is perceived as an aesthetic and spiritual achievement.

When I am not in a crisis, the other perspective is that of the mundane, the everyday world. It is a much smaller view. But that view includes the people in my life who I care about, and the projects that matter to me. In short, I can see the things that make my life worth living.

The other concept is that of a dialectic, particularly as it is used in Dialectical Behavioral Therapy (DBT). The most fundamental dialectic of DBT is acceptance and change. I accept myself as I am, I validate myself, understanding that there are reasons for the things I do, including self-injury, and they make sense. But at the same time, I can work to change, to build a better life. The dialectic, or two concepts that appear to be opposed to each other, need not be literally contradictory.

Another influential understanding of dialectic is that it is composed of a thesis and antithesis, and when properly understood together, thesis and antithesis merge, transcending the dialectic, to reach a new synthesis. That is how acceptance and change can work together—by accepting oneself as one is, while at the same time working towards meaningful change, a new synthesis emerges, of authentic growth, fulfillment, and creating a life more worth living.

As the concept applies here, it can be true that I want to kill myself, and that I want to live my best life. They need not be impossible opposites. Instead, perhaps, someday I might be able to transcend the dialectic, merging thesis and antithesis into a new synthesis, allowing me to experience the benefits of suicidal ideation, sadness, and pain, while also creating a better, more deeply meaningful life—a life more worth living. And this too may be transcended to reach a final synthesis: the more my life was worth living, perhaps the more beautiful and meaningful will be my death.

#### 3

#### Motherhood, Work, and Mental Health: One Woman's Journey

Karin T. O'Brien

#### United States of America

've suffered from major depression and anxiety since I was 9 years old. I am 43 now. I suppose Lyou could say I'm in recovery, although the word recovery implies there is some permanent healing. With mental illness, there is no recovery. It is more accurate to call it a mutually agreed upon co-existence. It is always there, and I've learned to accept its presence.

I'm currently managing major depression with diet and exercise as I've had negative reactions to anti-depressants in the past few years. I experience joy; I'm fully present in the moment and deeply appreciate the beauty of life, my family, and nature. I love walking in the forest and observing birds and native flora. I connect deeply with my family and friends and feel like an indispensable contributing member of society. I feel like I have space to breathe.

It hasn't always been this way. Sometimes, even now, the dark cloud still follows me. When I want to recover and rest, I'm reminded by my ever-filling inbox that I have obligations at work that demand my attention. In times like these, I feel like I'm not enough.

This is the biggest stigma of all: the one I hold against myself. There is so much self-depreciation, so much beating myself up. Why can't you just finish this project? Why can't you just cook dinner every night? Why do you have to be so much of a sloth!?

I am exhausted and also continuing to fuel the exhaustion by constantly battling myself.

A wise therapist once told me the story of a person who was playing tug of war against a giant, huge behemoth of a monster. The person was yelling, cursing, struggling, pulling, straining, hurling themselves against the weight of an immovable being. It was an unwinnable war. However, there was a way to move forward:

Drop. The. Rope.

Not in a macabre sense like mailing it in and giving into depression and anxiety—but make the deliberate decision to stop fighting against the immovable beast. Drop the rope and walk away. Choose a more noble fight. Rest. Feel well.

I understand needing to provide accommodations to people with physical disabilities—but realizing there may be a framework to assist me with a mental disability is the next step in my journey. For years, the stigma that I've carried tells me I am not capable enough or not achieving enough. However, if I drop the rope and look through the lens of this disease and see how much I am thriving despite being afflicted, I can see myself in a new light and walk away from the stigma.

The stigma has affected my life by allowing self-limiting beliefs to drive my self-worth and sabotage advancement. I'm a successful engineer, and yet, there is doubt. Any time I have to take a few steps back to catch my breath to feel grounded, it makes me feel less than worthy. Because a "normal" person would be able to function despite tremendous stress. Is this what work is like for normal people? Does everyone deal with this amount of stress? Why can't I just let it roll off my back? Why does it creep up, grab my legs and arms and drag me down in the abyss?

After my kids were born, we were hyper-aware of the potential for postpartum depression. It was no surprise when it settled in months after each child was born. So many of those early moments are drowned in the deep dark clouds. How many smiles did I miss? How many smells of their sweet fuzzy head did I ignore because I was wrapped in my own blanket of hopelessness? I had support: an engaged and active husband, friends, family, a great therapist, and amazing doctors with a cocktail of effective medicine. Even so, I felt rage like I had never felt before.

I did the hard work in therapy. I did the best thing I could for my kids—and let them see me process my feelings and anger. Was it traumatic? I'm sure. But I also think allowing them to see my humanity and fragility will shape what they see as a normal human condition. I overexpress my emotions, trying my hardest to give my kids the language to emotion and pain, so they might be able to process themselves and not shut down. I want to normalize depression

and anxiety, so they know not to suffer in silence, find it easy to get help, and not hesitate if they need medical help to alleviate their condition.

Mostly, I want them to know that I'm human.

Is it working? Who knows. I'm sure they will end up in therapy sometime in their 20s and 30s and complain about their mother, who just had *So. Many. Feelings* and would not shut up about them. We are all going to screw our kids up somehow—it's just a matter of how much and what kind of trauma they'll encapsulate.

The unintended consequence of motherhood has been the effect that motherhood, plus depression, plus work, has had on my career. Work has been quite the rollercoaster; stable after college but inconsistent after motherhood. I believe this is mostly linked to my inability to manage my mental health, work-life, and home-life all at the same time. My mental health always suffered with the stress of the other two. Taking a few years away to focus on my mental health and home-life, negatively affected my career. When I went back to work, I effectively started over.

I don't regret the time I took to focus on my mental health and family. I do regret that I accepted so much personal failure for my lack of career, which I thought translated to a lack of ambition. I talked myself into the rhetoric that I couldn't succeed because it was too hard with my delicate disposition. Now I realize maybe it was less of a failure of me to manage the different aspects of my life and more of a failure of corporate America to accommodate my disability.

Depression is a protected disability. Until this year, I had no idea. I'm thankful to have a supervisor who is doing his best to provide accommodations and was the person that pointed out that major depression is a protected disability. I can't believe I went most of my working life not knowing that classification! It was the first time in my life I thought, "Huh. Maybe everyone doesn't struggle with existing like I do." I have no idea which accommodations may have benefited me most in those early years. I wonder if I had known how it would have shaped the continuity of my career.

I understand needing to provide accommodations to people with physical disabilities, but realizing there may be a framework to assist me with a mental disability, is the next step in my journey. If I am going to continue to work full time, a major adjustment needs to be made.

Looking at work life through the lens that maybe I'm not incapable but just differently-abled has really shifted the perspective I have about my capacity to work. I realize that I am highly productive in short bursts and might complete the work of an 8 hour day in 1 hour. I shouldn't beat myself up for the non-productivity of those other hours. It's hard for me to slog through sometimes, and that has to be OK too.

I've worked tremendously hard to identify the triggers to my rage and my shut-down buttons. I've realized that a highly shifting workplace—fastpaced and always changing—is not an environment in which I thrive. Although I've made adjustments and have done my best to adapt, ultimately, I am in a role in which I am succeeding but not thriving. My depression and anger are triggered regularly, and I'm actively taking steps to improve my situation. I have dug deep and know more clearly what kind of job structure I need to help me achieve the balance I want in my life.

I'm well aware that no employment is without stress, but I also know that a career should not be a constant source of stress. This is detrimental to everyone, none more so than the depressive mind. Making this realization allowed me to make my own accommodations and modifications to manage my disability.

My failure to launch—or lack of professional success—is not directly related to my intellectual capacity but rather a function of the self-limiting beliefs of my own emotional and mental capacity. I cannot solve the complex, challenging problems faced by most businesses today if I do not have the space in my head to work it all out.

I've identified personal triggers: usually, something dealing with a problem I'm not familiar with, in a timeframe that is unattainable, with results that may or may not solve the issue—a failure-perfect storm. Being put in this same scenario over and over again doesn't set me up for success. It triggers my mind into a maelstrom of doom. I need air to breathe. I need time to think and work it out myself. I need stability and a methodical schedule. Like a large boat, my mind is slow to turn, and I'm completely aware of how I flourish in routine and wither in a fast-paced, changing environment.

If I were a doctor, I'd be a podiatrist—I would not be in the emergency room!

I took a new job in August of 2019—it was a perfect company on paper. An incredible team, supportive, worked hard but didn't take themselves too seriously, just as committed to building a fun team atmosphere as they were to serving their client. But the work was new, and the client was demanding. I'm great at learning new things, but not at learning from a firehose. I'm great at working out complex problems, but not in an environment where the finish line is continuously moved and the timeframe compressed.

It was the level 3 trauma center of an Emergency Room.

I worked with an incredibly accommodating boss to try to give space for the ins and outs of life—plenty of time for doctor's appointments, float therapy, mind therapy. Flexible working hours. Ultimately, it was not enough. I knew that if I wanted to have the ability to succeed and feel like I was crushing it, I'd have to make some pretty significant accommodations. I needed work that was slower changing, allowed me to think and stretch and make the huge amount of room necessary to care for my mental health.

I have submitted my resignation letter. I don't have a roadmap where this road may lead, but I know I'll move forward with my health leading the way!

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#### A Portrait of Trauma

Armando Quiñones-Cruz

#### Puerto Rico

"Clinical psychology tells us arguably that trauma is the ultimate killer."

-Lady Gaga

write these words only to try yet another way to heal, assuming, of course, that healing is possible. I seldom use the word 'victim' to describe

myself, as many a time we are all 'victims' of life in some sort of way. Be it in the form of a physical aggression, an abusive romantic relationship, a random assault on the streets, or a coercive boss at work, situations can victimize us in different ways. I would not call myself a 'victim' thinking that other people had it worse than me. With time I realized that, rather than forming a strong character, this avoidance pattern led to repress my experience, failing to find healthy coping mechanisms. Thus, I was never fully aware of the extensive harm that seven years of sexual abuse left within me. Even now, at 29 years of age, I am beginning to have full recognizance of it.

Some have posited that narrating traumatic experiences time and again helps ease the burden of pain and emotions that accompany the memories of it. Recently I was told that showing my vulnerability helped others cope with their own struggles. I never made a full account of what happened to me when I was ten years old. My mother took me to visit my grandparents' house. I was the youngest of three, my brothers stayed at our house, and I was left at my grandparents over the summer. That first night my granddad came to my room, pull the blanket off me, and started touching me, eventually leading to oral sex. This became an ongoing routine every time I stayed at their house during the summers and holidays for the next seven years. He would tell me that it was our secret game, and he made me promise not to tell anyone. At ten years old, this seemed like the keywords for something important, although I was not fully aware of it. Most of the time I felt ashamed and embarrassed of what would go on during those visits, being unable to tell anyone. During the nights however, more than ashamed, I was terrified. I would grab the blanket and clench it around me as if it would protect me from him. When I was old enough, I left my mother's house and went to college, thinking that my nightmare ended. My performance at school was not selfevident of any troubles at home or any abnormality. During middle and high school, I had excellent grades and was a student leader, spending most of the time in student organizations, school contests, and community service. I was also very engaged with my mother at church, but it eventually led to feeling guilty about the 'game' I played with my granddad. At home, I spent most of my time alone in my room, remembering those things he would do to me.

My self-worth was construed around my ability to please any man. Academic achievements had little importance as, in my mind, I was only worthy for pleasing men sexually. Eventually, I let strangers have sexual encounters with me since I was fourteen. Having experienced it with my grandfather, I saw it as "normal." Therefore, I would let a schoolteacher at my mother's school or a random guy at a public bathroom enjoy my body. During my college years, these sexual practices would involve consuming alcohol, cocaine, and marihuana. Being unable to foster meaningful romantic relationships, I developed a propensity for alcohol and used it every other day. All those practices became unhealthy routines for coping with low self-esteem and painful memories. I went to see a psychologist as I was starting to feel sad and alone, but after a failed hypnosis guided therapy, I did not return. At that session, the memories of my past were explored, and the long-repressed trauma was awakened. But this made me reject therapy altogether.

A year later, after graduating college, I suffered my first panic attack while receiving training for a job. Afterward, I went to a psychiatric clinic at the medical school and was started on medication therapy. However, the student doctor would read from the diagnostic manual for diseases a list of symptoms for me to assert or deny, and then assign one accordingly. This practice went on for several sessions, during which I received several diagnoses that in turn resulted in changes to the medications I was taking. The doctor would change the diagnoses every other month from post-traumatic stress disorder, borderline personality, bipolar disorder, and general anxiety. This constant change and unstructured therapy made me skeptical and wary, missing a lot of appointments and medications. After nine months in medication therapy, in 2014, I attempted to commit suicide by overdose, something that would happen again a few months later. I was still depressed despite the medications,

but I reckon that it had to do with the fact that I was drinking alcohol. After the second attempt, I had to quit my job, and later I spent three months at my mother's house. After the episodes of self-harm, I was formally diagnosed with major depressive disorder with anxiety.

Meaningless sex led me to not being able to enjoy sexual relationships with my romantic partners. Moreover, becoming an alcoholic turned me into a very volatile and angry person. Many times, I would find myself yelling at people at work. It also impacted my performance due to absences after long nights out, even causing me to lose a job in 2019 for not showing up without notice. After that time, I committed to drink less and have retained my job always. However, after meeting someone important in 2019 and moving in with him, alcohol became more of a problem. It caused many fights between us, many of which happened in front of his friends. Moreover, I sometimes rejected his approaches to having sex if I was sober because sometimes I would remember things from the past. On his birthday, we got into a huge fight because I mixed alcohol with benzodiazepines and ended up physically hurting him. After a few days, when I realized what I had done, I decided to quit drinking for good and committed myself to the hospital. When I came out of it, he was waiting for me. We continued to live together and try to work things out. Although I had continued to go to therapy and without drinking alcohol, he decided that it was best to part ways. Now, I still carry the shame and the guilt of all the misdeeds I caused him.

After these seven months without drinking, I can recognize that alcohol has been a catalysis in most of the experiences for the past seven years. Mixing alcohol with my medication did not provide any result, which led me to stop medications and, in turn, feel worse. It was also due to alcohol that I was engaged in risky behaviors with sex and other substances. Along with alcohol, cigarettes are not part of my daily routine anymore. However, recovering from episodes of depression and selfinflicted harm takes more than quitting alcohol. It also takes more than forgiveness. One of the most difficult things for me was realizing how harmful alcohol has been to my life and how much damage I have caused others—also, recognizing that I was ill-equipped to handle things on my own and that seeking help also required commitment. This commitment requires me to adhere to medication without alcohol consumption. It also entails participating in therapy, engaging with the exercises that I am assigned, and promptly looking for another if something is not working with my therapist. Leaving therapy altogether has caused relapses and continuity issues.

Despite the three times I have been in the hospital, the instances have been voluntary and for my own benefit. Self-harm can be a persistent, insidious thought, and our poor impulses are a danger. To acknowledge it takes a lot of effort. Besides stabilization, full or partial hospitalization provide great ways to receive group therapies. Through these, I have been able to engage others who experience mental health issues. This provides encouragement and support through peers of any age. In addition to the hospitalizations, I am consistent with visits to the psychologist, even with video calls, and continue taking my medications without any alcohol use. Recovery is an ongoing effort. Besides abstinence from alcohol, I am focusing my efforts on developing my self-esteem and grasp my true worth. Through mindfulness and group sessions, I have been able to recognize my own accomplishments and know their worth. Not only will this help me assert myself as an individual, but it will be beneficial for fulfilling my master's degree that I started last year. By developing healthy routines, including planning my weeks, practicing yoga, and joining professional associations, I am engaging in things that do not require alcohol.

To be a healthcare professional and suffer from a mental health illness can certainly be challenging. Since mental health is not something that is physically perceived, many times, when one refers to feeling 'unwell,' it is deemed fictitious. I have been referred to as 'bipolar' due to poor impulse control at work. Last year, after I was discharged from a partial hospitalization and came back to the office, several coworkers approached me to know how I was. It turned out they knew that I was in a mental health facility. Later I was told that my supervisor disclosed details of my health to my coworkers. Since then, I have been skeptical of sharing any health issues with my manager while refraining from pursuing any sanctions. Though major depressive disorder is a recognized disability under ADA, no approach was made at that time for any accommodation I may have needed. Notwithstanding this, and knowing my rights, I have taken further steps to secure my position and guarantee that I am not discriminated against. My job metrics and performance are outstanding, but the failure of my manager to act on my behalf has provoked some concerns from human resources. But I am confident that with time, all things will work out well.

If anything, I have learned that we only live but once, and all that matters is what we do this time around. To those individuals who may be struggling with any mental health disorder, I would say that we are not just a diagnostic, a medication, or plain symptoms. We are humans and that should be our identity. With this, I mean to say that a diagnosis should not define what we are, or who we are. A diagnosis should not impose limits on our lives. If anything has been characteristic through my years is my reluctance to give up. Yes, I have manifested a desire and have attempted to stop my existence. But each time that I fail to do so is a new opportunity to continue working hard and become better than I was. Often, I reckon that self-isolation leads to more depression symptoms and sadness. However difficult and painful as it might be, it is necessary to interact with others, even with those who also suffer from mental health issues. Sometimes we might feel the need to exclude everyone or think that we do not have anyone who cares enough. Past experiences, however, have proven me otherwise and by reaching out, I have identified many new support persons. Through an ongoing process of mindful awareness and introspection, support networks and therapy, I further assert my new self. When we might not find direction in our paths and struggle to figure out where to go, know that there is only one way to move: forward.

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#### A Soldier's Unseen Scars

Jason Jepson

#### United States of America

oon after I entered the world, I received my first scar. As an infant I had pyloric stenosis, a blockage between the stomach and small intestines. I'm told that it was a rather simple fix, but it did leave a large scar on the right side of my abdomen. As a child the scar was more of a curiosity than anything else. I remember making up funny stories to tell my friends about how I got the scar such as: "I was wounded in a shark attack."

As I grew older there would be other accidents that left scars as reminders of milestones in my life. There were scars on my legs and elbows from my time as a high school athlete playing lacrosse, basketball, baseball, and football. There is the scar on my thumb from one of my first jobs working in a restaurant kitchen where I had an unfortunate encounter with a slicing machine.

There is a scar on my chin that I notice whenever I look in a mirror. I got that scar when I was in the Army, driving a M113 tank. When I hit a bump in the road, my head slammed into the cockpit, and I ended up with a nasty cut that required stitches.

The scars that have had the most profound impact on my life, however, are not ones that left a mark on my skin. These scars, while invisible to the eye, have left a lasting effect on my life in ways that go far beyond what my visible scars can tell about my life

In 2003 when I entered the United States Army, I took those visible scars with me to Fort Knox, Kentucky. I was taking a break from college when I joined the Army, and the idea of a military experience seemed like a good fit for me. After basic and advanced training at Fort Knox, I was assigned to my first duty station at Fort Irwin, California as a 19 Delta Cavalry Scout. Although physically I had met all of the requirements to become a soldier, I was woefully unprepared for the emotional scar that would wound me in a way that I never expected while I was there in the desert. That wound was the result of a hazing incident that occurred when a few of my fellow

soldiers tried to break my spirit by duct taping me into a fetal position. The desperation I felt during that incident broke something loose inside me and left a mark on my soul that would change my life forever.

After that hazing experience, I was a different person. I have since learned that mental illness can be underneath the surface, waiting to push its ugly head out to control a life. The results of that hazing incident produced a different Me—someone who was suspicious of others, thinking they were going to do me harm. I was now paranoid and fearful of everyone around me. I thought people were stealing from me, talking about me in negative ways, and making fun of me. All this made me suspicious of my fellow soldiers, and I began to isolate myself from them. Of course, they saw me as a nonconformist, and they kept trying to get me to follow orders. However, in this new altered state, I was confused about every aspect of life.

One particular delusion I had was that I had a special form of ESP, a special power that would benefit the Army. I thought God was going to use me to teach soldiers to be self-aware, so I referred myself to the mental health clinic on post. No one in the clinic was impressed with my special powers, but instead I was referred to the hospital for psychological testing and received a diagnosis of schizophrenia.

Specifically, I was diagnosed with schizoaffective disorder which is a chronic mental health condition characterized primarily by symptoms of schizophrenia, such as hallucinations or delusions, and symptoms of a mood disorder, such as mania and depression. I would go on to learn that my brain disease would leave an internal scar that would remain with me forever, that I would take medication for the rest of my life, and that my future would be a battle to manage the symptoms of this disease. I was twenty-three years old, young, inexperienced, and facing the greatest challenge of my life—something I was totally unequipped to handle. Thankfully, I received an honorable discharge from the Army with a 100% disability rating.

When I returned home to Virginia, I was not the person who had left. I refused to accept my diagnosis and, without the medication that I was supposed to be taking, I began acting out in ways that were extremely detrimental to my health and well-being.

I didn't understand the voices and delusions inside my head. I was angry that my parents didn't understand what was going on with me. In my chaotic rants, I tried to make them accept that I could fight this on my own, without medication. Although they did their best to support me by researching my diagnosis and by attending a group for parents of mentally ill loved ones, I believed that they, too, were hearing the voices I was hearing and were part of the conspiracy to cause me harm. Having made eye contact with me, my parents were listening to the wrong voices, and I wanted them to just listen to me.

I had a savings account that was quickly depleting. I would not take my medication, and my head was full of voices not understanding who they were talking to. My parents finally made the hard decision to call the police because I had become a danger to myself and even to them. It could have ended badly but even I was tired of the voices in my head.

It has been several years since I was committed to that psychiatric hospital. Today I am happy to say that I am in recovery. My recovery has not been in weeks or months, but in years. During those years I have gone through trial and error periods with my medications, and with the help of my doctors and with my own patience, I have reached a place where my symptoms are manageable. Along with an antidepressant, I now take a monthly injectible which eliminates the need for remembering whether or not I have taken my meds. I still have symptoms, but if my symptoms are getting in the way of life, I know I can have a conversation with my doctor about that.

Knowing what is going on around me is an important part of my continuing recovery. I have learned to examine the evidence around me to determine whether what I think is happening is part of reality or non-reality. If there is no evidence, then it is my brain disease talking. The voices are still in my head. Sometimes they are in the form of commentary-sometimes insulting voices, like conversation, as if the person is in the same room as I am in. One delusion is ongoing—a voice in my head of an old man who likes when I mess up or just waits until I do so. Sometimes they are the same voices I heard in the desert or on the evening when the police took me away from my parent's home.

Perhaps most importantly, I have accepted that I have a mental health diagnosis. I have a brain disease that can affect my perception of what is going on around me. I take a medication that helps with that—just as a person who has heart disease might take a medication to relieve his symptoms. I have decided not to be silent about my diagnosis. There is nothing that I have to be ashamed of. Some people may not understand my diagnosis, but if they give me the opportunity, I can tell them what it's like to live with a brain disease.

Time can heal all wounds, but the scars on my psyche will always be there where I can feel but not see them. My ongoing recovery is a sign that healing is taking place. In my recovery I have chosen to not dwell on the losses, but to live my life the best I can. Part of that purpose is to continue to shed light on mental illness through my writing of first-person accounts and to fight the stigma that surrounds mental illness and prevents people from getting the help they need. Through my writing and advocacy, I have become the educator for those who need to understand what life is like for someone living with mental illness.

Dennis Leary said, "Happiness comes in short doses." I think that means: grab hold of the simple things. That can be a walk around my neighborhood to observe nature, cup of coffee or tea, or listening to some Miles Davis jazz. Recovery, for me, is about embracing life again. What follows is a poem I wrote to describe my life now. The poem is entitled "To Live Out Loud."

To Live Out Loud And in the grips of insanity what carries my hope what keeps me laughing when the voices seem to control my mood? I've often said, "Once you've lost it, you can't lose it again." I laugh, but no one else does. Normal—so boring you might say. When my imperfections shine like the lines of poetry, I am a writer; unnoticed, however, changed by the real world. In adulthood I value my smile.

The struggle is beautiful, once you can look back on it. Now, I have settled, but these words might say otherwise. I am alone in the bliss. As a young man, no one told me I would be so content at this age. I laugh, I sing, I dance, but there is still fear that I am trying to ignore— I ignore, that I might live out loud.

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#### Half Dead

Jessica Morgan

#### United States of America

never thought I would be alive, let alone survive. I grew up not understanding what mental health was. As a child, I felt self-conscious about the space that I took up. I had countless nightmares focused on death. These concepts were much too complicated for my feeble mind to comprehend. I was ten years old after all-in the prime of my life. I didn't understand what this pain was. "Why are you sad," an elderly woman asked while I sat on the bench in a shoe store. I was around twelve years old. My mother and two sisters were browsing shoes on the adjacent aisle. I ignored the woman and forced a smile at her. After all, my mother told me to never talk to strangers. I wasn't going to be subjected to a lecture for disobeying her. The truth is that I didn't understand why I was sad. On the outside, I had my mask on. The mask that I wore to school and in public places. I was pretty good at hiding my true feelings. Not on this day. I felt solemn. I couldn't muster up a smile to prove to that woman that I was ok. My mother overheard the woman and said something to assure her that I was alright. Was I? I didn't know how to communicate what I was feeling. There was a familiar empty feeling that I couldn't shake off. I was comfortable with it, but I wondered if there was some piece missing. I felt like one of those thousand-piece puzzles with one piece hiding in the corner. I couldn't quite reach that piece, but I knew it was there. I knew it was that piece that would give me the much-needed serotonin to make me all better.

By the time I arrived in high school, I started to ignore questions about my mood and began to obsess over my body. My body was literally dripping from the seams of my school uniform. I felt as if my flabs were like waterfalls that couldn't be contained by my clothes. I started covering up with dark-colored jackets to give a slimming effect. My body also started being the topic of conversation in my family. "I never wanted fat children," my mom told me in one of her seemingly innocent lectures about the ways that my body flows. I felt numb. I was used to her criticizing my appearance. I never thought she would resent what I had become. Part of me didn't care. I wanted to adhere to the strong black woman archetype so bad. I wanted to be superwoman, but I couldn't. I was too busy working out a plan on how to kill myself. I couldn't fit in no matter how hard I tried. Covering up felt like I was hiding my battered body from the world. The scabs from my body were just falling off with nowhere to go. I knew that if I killed myself that I would be blamed for killing myself rather than the state of mind that got me here. I had to find something to soothe myself. I always loved food. How ironic it is to medicate with food for being called fat. As a result of poverty, I couldn't medicate with food until I was in college in 2013. I ordered out nearly every night from Dominos to soothe my pain. Each slice of pizza that I ate made me feel guilty. I kept having flashbacks to that bathroom floor back at my mom's house, where I poured my tears into the toilet and attempted to flush them away. I couldn't flush this down. I was drowning. I felt trapped between my dorm room's four walls.

As the years went by, I kept feeling this way—a seemingly sick to my stomach kind of feeling. It finally all came together in 2019. I had my first experience with dry heaving. I was sitting in my apartment trying to prepare for a presentation. I started to feel really stressed. My heart started beating out of my chest. I started getting nauseous. My mouth started feeling wet. I felt something trying to come up. I realized that I was about to throw up. I ran to the sink. There was a pile of dirty dishes blocking the drain. As I struggled to push them aside, I made vomiting sounds. I leaned over in the sink. Nothing came out. I was confused as to what was happening to my body. Had my body finally failed me? I knew I struggled with bingeing, but I at least thought I had a few more miles in my engine. I felt like I was about to die. The repetitive vomiting sounds kept repeating. I finally vomited. I tried to slow my breathing. Inhale . . . exhale. Slowly. My nauseousness started to go away. I sat up slowly and reached across the stove for my bottle of water. I kept slowing down my breathing. Inhale . . . exhale. I was finally on the other side. I kept steady with my breathing while asking myself what the fuck did my body just do? I eventually found out that my dry heaving was a result of my social anxiety. At this point, I rejected the idea that I had anything that resembled a mental illness. When I thought of mental health, I didn't see my face. Sure, my public health education afforded me the luxury of now understanding what mental health was, but that wasn't me. I did wonder if what I experienced was a panic attack or some form of it. When I dry heaved again, I knew I had to do something. I was tired of living in this new normal. I had to reach out. I needed therapy.

Seeking out therapy was relatively simple. As a student, I have access to therapy through my school. I scheduled an intake appointment and the counselor set me up with my first therapy session. On the day of my first therapy session, my stomach was in knots. As I walked to Student Health, I kept reliving the memories that brought me to this moment. Memories of the times I said something stupid and how I became an outward shell of myself. Maybe she could fix me. Food didn't seem to work. I checked in. I appreciated that the secretary only asked for the first three letters of my last name. I don't want people to know I'm here. I'm embarrassed that I couldn't keep it together. I try to get a seat near the back, but someone is there. I don't want to take up all of the room. I sit towards the front. Maybe that'll make it easier for the therapist to spot me. It was my first time, after all. I sit down. It's my . . . body. It can't all fit in the seat. Hopefully, no one is noticing. I close my legs tightly to shrink myself. I start to fidget with my fingers. I couldn't bear this wait. I mentally paced back and forth. Keep it together, girl, I kept repeating to myself. I wish I could be strong. I always have my head down. There was a shadow nearing me. I looked up. A woman whispered my name. I looked up in agreement. I got my things to follow her back to her office. She invited me to sit on a tan-colored couch. She introduced herself as I observed her tiny office. What is that incessant smell? It's so familiar. Lavender! I finally noticed her diffuser on her bookshelf. It's so comforting. Inhale . . . exhale.

"Why don't you tell me your story?" she asked. I paused for a second. I had to be vulnerable and tell her everything. I'm on my own and have to take care of my whole health. Ultimately, I decided to hold back. "My parents divorced when I was twelve and I resented my mother for leaving," I said, in a few words. I felt like I was stuttering. My social anxiety kicked in. I stopped talking. She gave me an overview of how therapy worked. It sounded intimidating. I never had someone deeply listen to me. I was so used to feeling like I was stuttering and abruptly ending my sentence for fear that I was sounding stupid. Not to mention, I felt that I was being judged by the ocean of flabs on my body. I couldn't tell her that. I know it's all in my head. I felt dumb.

Over the next few months, the therapy seemed to work. I learned to challenge my negative thoughts with positive thoughts. I was finally able to find medication that worked for me, but I was skeptical. I felt that medication halted my creativeness. I was so used to being sad. I wasn't used to feeling hopeful for the future. That soon changed. I was out shopping and got an email that reignited it all. I made a B—B as in below average, beneath. I kept telling myself that this doesn't bother me. I kept mumbling that to myself while I sat in my car motionless. I had constant flashbacks to middle school, where one of my teachers said that I needed a whooping for making a B. At that time, I thought a B was fine. My inner perfectionist wasn't refined back then.

Now, I'm sitting in the car, nearly in tears over a B. Keep it together. I put on my mask and go inside the store. When I arrive home, I keep telling myself over and over that a B is ok. I know it isn't. I worked hard to have all A's on my transcript and now it's ruined with this B. I do deserve that whooping. I'm so tired. I just want to sleep this pain away. But I can't. I'm up thinking about how to kill myself. I hate being in pain, so this needs to be quick. I'm driving now. Maybe I can crash in the ditch. It could be instant. Then, I won't have to bear this. It would be all over. I'm going about 80 on the interstate. I could just crash on the side of the road. I have to shut down my instincts to apply the brakes. Why are there so many people out today? I don't want to hurt anyone. I should be the only person that gets hurt. I deserve it after all. Maybe pills would be better. I slow down to the speed limit. Yeah, pills would be painless. I won't be in anyone's way. No one would find my body until a few weeks later. I don't call my parents and I don't have many friends. I live alone. If I swallow all of these pills, that would do it. I could die easily and painlessly in my sleep. I would finally sleep like a baby. Oh, how I admire the dead. They seem so peaceful. I wouldn't be in the way anymore. Maybe I would lose some weight while I die. I hate for people to go through a lot of trouble finding an appropriate casket for me. I should just burn. It's what I deserve. I won't be missed. Nobody is coming for me. I can see that cliff. All I have to do is take one step. I can't move though. My conscious fails me. I need to get this pain out of my head! I'm so tired. I probably need to tell someone.

I finally had the courage to tell my therapist in an email what was happening. I was at the car shop when she called. She was worried that I may hurt myself. I didn't understand her worry, but I assured her that I usually never go about my plans to kill myself. I've been dealing with this for years, so I understand *me* better. She scheduled me for a crisis appointment. I went in for my appointment and told her what started this all: my feelings of inadequacy. She helped me to do a safety plan to show me that I'm not alone. It was very hard for me to understand. I'm not used to exposing my vulnerabilities. I would like to die, but I can't let my

mental health be the hill that I die on. I don't want to become death. I just want to be good enough.

3

#### **Embodying Bipolar**

Julia Knopes

United States of America

The first psychiatrist I ever saw handed me a pencil and a piece of paper. "I want you to map what's happening now," she instructed, "the highs and lows, the duration and intensity of each." And so I drew a line on the page, at first a high plateau, which suddenly dipped low into depression, and then rose up again to hypomania. The physician took the paper back and drew another line, this one low on the page with sparse but notable spikes upward. "Everyone with bipolar disorder cycles differently between moods and symptoms," she noted, a thumbprint by which each bipolar person is known, "so now draw me your symptoms in the past." "I don't remember much," I admitted, my persistent hypomania a thief of memories through the rapid blurring of thoughts that left, and still leave, largely bodily sensations behind. She gestured to the page regardless. And so I drew another line, the story of my past, longlasting periods of mania plummeting into shorter dips of blank euthymia, and then-more recently at that time-into the long spells of depression indicated by a flat, low scribble.

I cannot remember when bipolar disorder first threaded itself into my psyche. What remains is an impressionist account of my illness from as early as I can recall. Bipolar disorder emerged in my body before it swelled in my brain. Between middle and high school, it began as agitation: the agony of sitting still, tremors in my hands, peeling off the skin of my fingers until yellow bubbles of infection surfaced around my nails. I rubbed my eyes until the cheap drugstore eyeliner melted away, biting my nails until the polish I wore flaked off like shed scales, products bought with the cash my dad slipped to

me for after-school walks to the local pharmacy. At some point, mania emerged, and as the restlessness worsened, my speech became rapid and incoherent as irritability ached like needles beneath the skin. These are disconnected memories, attached to my body and not to my thoughts or my surroundings, leaving them out of context to any changes in my sense of self. And then, without warning, the agitation would ebb away, emptying me of feeling until mania returned again as it pleased. "I'm so bipolar," people without the disease say to describe shifts in happiness and sadness that are within normal range. That misconception fails to represent the physical symptoms that bipolar brings, a storm in the brain manifested as bodily suffering.

And so that is how it went on, in the beginning, cycles of agitated highs bottoming out to numb euthymia as I approached high school graduation. My family's socioeconomic status buffered my disability so that I could function, allowing me to spend summers and evenings without employment, free to rest. Privilege softens the ground upon which people with mental illness fall, but if one is dropped from the towering heights of mania, they will still shatter when they land. At my private liberal arts college, my hypomania persisted. It left my thoughts indistinct, but I have fragmented nostalgia of that time: the tartness of raspberry vinaigrette on the dining hall salads, the foamy lather of Aussie shampoo in the tiled dorm shower, the smell of cannabis tickling my nose when I spent late nights at the Beehive Coffeehouse in Pittsburgh. Those memories are soothing now, but during that time, I still felt agitated. I was overly eager to discuss in class, my brain rupturing with rapid thoughts and words I couldn't bear to contain. This enthusiasm earned me top grades, at the cost of significant discomfort. I do not recall much topical knowledge from my undergraduate years, though I retained the mechanism of critical thinking as if the skill was embedded deep within me as a reflex rather than conscious knowledge. My hypomania soared through third year, and when the discomfort became too great, I met with a campus therapist conveniently paid for by my tuition bill. Generalized anxiety disorder, she labeled my woes. I resisted the antidepressant medication the therapist

recommended out of a sense of stigma. Taking medication would mean admitting I was mentally ill. My fear of antidepressants was inadvertently to my benefit, as these drugs alone would have triggered worse mania. I was willing to attend therapy, however, because it felt characteristic of liberal, educated white women like myself: listening to NPR, sipping water out of reusable bottles, paying for the luxury of professional validation.

Higher education itself became my primary, fickle therapy: one with a significant price tag attached. It worked my brain like a jog on a treadmill, pushing my mind through difficult intellectual dilemmas enough to make my brain too tired to feel much of anything. In that way, hypomania fostered intense curiosity and dedication, especially around human behavior, leading me to a doctoral program in anthropology. I was content in my first years of study there, unburdened by the need to work beyond the hours attached to my assistantship funding. My hypomania eased, though it did not relent entirely, and I recall that time with clarity. I studied socialization and identity, culture and ethics, under the warm light of the shabby sunroom in my rented apartment. I drank smoky lapsang tea while discussing complex theory with other doctoral students in neighboring academic departments. I attended therapy to rattle off past traumas, but never to contend with the reality of my illness. Life continued, relatively unimpeded.

The lull did not last. As I completed my ethnographic fieldwork and set out to write my dissertation, rampant hypomania set in. Perhaps the transition from research to writing triggered an episode, but writing was and is my refuge. I felt then as if the symptoms stepped through the threshold of my mind like an uninvited houseguest. As it had before, hypomania set fire to my psyche. My thoughts were darting wildly, as tremors and sleeplessness racked my body. The only solution, I believed, was to write. And so I did, pouring endless, uninterrupted hours into completing my dissertation. I have few memories of that time that don't involve furiously typing away on a laptop with mugs of tea in arm's reach. It was early summer when I began, and my energy soared in the long daylight. One day, I wrote twenty pages. Giddy and talkative, I became too overbearing in the company of others, at least in my own estimation. I isolated myself in my apartment.

I sensed something was wrong, but what would I say to a physician about it? "I'm here because I'm being hyperproductive." Capitalism silenced this complaint. I was a hard worker. I did not need to be lassoed into submission with medical treatment, I thought. Within less than four months, I had a complete, compelling first draft. Some of my peers were openly jealous of my progress, unaware that writing was the only way I could work my racing brain into exhaustion to ameliorate my madness. This, too, was a privilege, as I had financial support from others that allowed me to drift into my scholarship with little worry.

And then, I turned my draft over to my doctoral committee, who required time to review my work. I now had nothing to occupy me. For the first time, depression swallowed me whole. At first, a slowed mind and decreased energy was such a break from hypomania that I felt relieved. Until, that is, I slept for hours, body heavy like cement, dizzy when I stood. That time was a fog, full of the bright light of my laptop screen as I streamed movies and television on Netflix. I felt hopeless and disconnected, but the physical sickness was worse, the feeling of fatigue so severe that showering was a monumental effort. It is hard to remember much else amidst suffering, the pain entering into the foreground while events and places became frayed backdrops onto which disease was projected. I relented whenever the depression caused such intense chronic pain that I couldn't function at all. I scheduled my first meeting with the psychiatrist who invited me to draw my illness. She diagnosed me with bipolar disorder, weeks before I graduated with my doctoral degree. I was too sick to reject pharmaceuticals any longer.

What followed was two and a half years of medication changes. I lost count of how many drugs I tried after ten. Unlike an antibiotic that can cut through microorganisms like a scythe and, ideally, promise acute eradication of illness, psychiatric medications do not offer complete or even prompt recovery. Indeed, I had to be willing to become even more sick every time I titrated the dose of one medication down, and then increased the dose of a different drug. The side effects oscillated as I switched: all while I adjusted to multiple medications at the same time as my bipolar disorder evaded monotherapy. I started one antidepressant that made me feel hazy for a week, and then resulted in sweating so severe I couldn't sleep for months, after which I surrendered and lowered the dose only to feel sore and drained for another few weeks. I began an antipsychotic, which had no effects at first, until it made me pass out on the sidewalk outside of my house, splitting open the skin of my wrist. I bled all over a paper towel.

This went on until the drugs were calibrated. "You're a responsible patient," clinicians would tell me, by which they meant compliant, and compliant meant willingness to become sick over and over again for years until a solution, however partial, could be found. Eventually, I settled on a series of pharmaceuticals that did not eradicate symptoms, but spared me from the worst of exhaustion and agitation. The crown jewel of the five pills I took each day was a next-generation antipsychotic that held my sanity hostage at the price of \$1800 a month, had my insurance not covered nearly all of the cost. My physicians asked me if the drugs were working. I told them I could put away dishes and fold laundry now without fatigue. I told them I only felt as if I was bursting out of my flesh with agitation some, but not all, of the time. It was progress.

When I draw a map of my symptoms and moods now, the highs and lows are blunted, yet nevertheless fluctuate in continuous waves on the page. The line does not form a clean circle, meeting back at its beginning. It has no end, always moving forward on the graph. That is the reality of chronic conditions, those illnesses which too often have no narrative closure. My psychiatrist and I still monitor my condition, tinkering with medications, paying attention to the impact of social stressors on the perpetual course of bipolar disorder. Memories characterized by bodily sensations often remain free from attachment to particular events, yet what remains persists on the maps I create, visual and

verbal. The neverending line is at once a source of despair that I will never be free of the course of my mental illness, and a source of hope that I am always moving forward. And on that line, bipolar disorder is the lantern that lights my path, a fire that burns, and burns, and burns, and that can never be extinguished.



#### Seeking Balance and Recovery in a Life **Near People Who Care**

Nikolaos Kougioumtzis Translation by Valentini Bochtsou

#### Greece

was born in 1977 in a small village of North-Eastern Greece. I am the fourth out of five siblings. My mother suffered from schizophrenia. I mostly remember her feeling unwell and I now realize that she faced serious difficulties due to her symptoms. My father repeatedly mentioned to me that he was the one who delivered me. My childhood memories are not pleasant; my mother was kindhearted, but I felt completely neglected by her. My father was supportive; I keep his words in my heart, I now think that his advice was soothing to my soul.

Everyone at home seemed to face their own challenges. Things at school were also difficult because I had learning difficulties and no help with studying. As time went by, things were getting worse, because my father had a heart attack and could not care for us all. At the age of 10, I was assigned to a foster family in Athens due to the difficult circumstances at home. My father approved this, hoping that I would have a chance for a better future, while growing up in a more stimulating, stable environment. I can still recall the day he accompanied me to Athens, by bus. I was wearing brand new shoes, clean clothes, my hair was neat and we enjoyed rich, tasty meals at bus stops, on the way. I also remember his eyes filled with tears, while we were saying goodbye. He died a few years later.

My foster parents had a big house in a quiet suburb of Athens and at that time they raised four more children, three boys and a girl, also coming from families with psychosocial difficulties. They were Catholic and consequently very strict in my upbringing. I remember myself being shy, socializing mainly with my foster siblings and adult family friends, not being able to invite my own friends to my house. Puberty was a difficult period; I didn't get along well with my mother and teachers and my father was distant. I managed to graduate junior high school, despite my learning difficulties.

When I became 16, my foster parents insisted in me moving to a city near my homeland, where I enrolled to a technical school in order to become a plumber. I decided to go with mixed feelings—on the one hand I was happy to get away from the strict foster family environment but on the other hand I definitely felt unwanted by my foster parents. I adapted fairly well. However, I thought I was different from other teenagers, I was anxious about being consistent and good at my work as an apprentice. I tried hard to focus on that, but my efforts were not much appreciated by my employer, who paid me a very low salary without social security. I also have good memories, we used to have good times with fellow apprentices. We were frequently going out for a meal or drink.

At the age of 18, I served my military service. It was a good experience, because my superiors were kind and rather protective towards me. 18 months later I returned to Athens, started to work, but also started feeling psychologically unwell. I felt that my mind was blurry, my interests, personal ideas and wishes were all getting mixed up. I became extremely emotional. Things became intolerable and seemed extremely complicated. I started having severe headaches. I felt tense. No one at home could understand my situation and I remember quarreling with my mother on a daily basis. I cannot remember those days in detail, but I cannot forget my mother's frightened look after a fight. I felt extremely frustrated by my symptoms, I was very lonely and I decided to take some acupuncture and yoga sessions. This effort proved in vain. My symptoms escalated. I felt worse and could no longer manage my thoughts and behavior. People near me seemed embarrassed by my actions. I had difficulties distinguishing what was a fact and what was just a thought of mine.

I ended up visiting a psychiatrist and I was diagnosed with schizophrenia. I took medication, which helped me a lot, and I managed to regain stability again without being hospitalized. This proved too much for my foster parents though, who could not manage it at all and proposed that I should move back to my homeland. The mental health organization I visited for my therapy in Athens, also operated social psychiatry services near my homeland so within two months' time I decided to move there and stay in a protected apartment with a flat mate. During the 20 years that I have been living here, we have preserved communication with my foster family. They have visited me twice combining holidays. I have also visited them in Athens four or five times.

The years that followed were productive with many happy and less difficult moments. I cultivated my personal interests through several activities. I learned how to cook and keep my place tidy and clean. I decided to save money and invest in making the apartment a true home. I decorated my room. I bought several home appliances that would make our life easier and comfier. I did not manage all that by myself. We did it with my flat mate, George. We gradually became best friends, and built a strong relationship. He is like a brother to me. This was not an easy thing at all, because we differ a lot. We have both compromised on many issues throughout the years. Sharing our way to recovery brought us close and we managed to discover common paths and interests, as well as teach each other a lot.

I met new people, collaborated with good therapists, I finally felt acceptance. I have also worked in a vocational agricultural program for many years. The contact with nature really helped me. Touching soil, watching seeds grow into plants, harvesting, caring for our pets were so fulfilling. Of course, there were also many difficult moments when I felt stressed and tired. This project was synonymous to teamwork. Eight service users worked there. After 20 years of hard work in this

program, last year I decided that I needed a break to rest and think calmly how I wanted to continue my professional route.

On a personal level, I am in a long-term relationship with a woman who loves, cares for, and understands me. We have been together for more than 15 years. We soon realized that it would be difficult to start a family together. We were afraid that if we had children, they would also suffer from mental health problems, like the two of us. I very much enjoy her companionship and affection; it is like the missing piece of my soul's puzzle finally found its place. I try to be as supportive as possible to her own difficulties, both everyday and deeper ones.

Sharing my story in public is very important to me-actually it's like a dream coming true. I always wanted to offer my help and experience to others, especially those facing similar challenges. In a nutshell, things that I found important and helpful in my personal recovery path were: good collaboration with therapists; building with them a bond of trust; and setting goals with respect and consideration of my personal views, interests and choices. Avoiding disturbing stimuli, finding the motivation to participate in activities, claiming and finally gaining different roles as a person, is what gave a meaningful and fulfilling sense in my life.

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#### Your Unique and Beautiful Brain

Sara Schley

United States of America

t first glance, when you meet me, you'll find a successful business sustainability consultant, women's empowerment leader, and Shadow Work coach. Since 1993, I've led large systems change initiatives at more than 50 enterprises. I live on a dozen acres—organic garden, solar panels, trout stream, sugar shack—in the woods of Western Massachusetts. We had two feet of snow this morning, and when I've finished writing this, I'll strap on my skis and head out the front door for a romp. I'm a mother of grown twins, recently launched to college, and have been married to a "stand-up" guy for 27 years. It looks like a blessed life, and it is.

Come closer though, and I'll tell you this: I've suffered from a debilitating brain disorder for four decades. Like Persephone in the underworld, I have been caught in the grips of an overpowering force. For months on end, prisoner of the darkness. A relentless, burning terror.

Twenty-five years into this struggle, I learned that I have a brain pattern known as "bipolar II." The roman numeral "II" here is the key distinction. Because bipolar II presents itself clinically as "normal" depression, it is mostly undiagnosed or misdiagnosed. The results are deadly, as the standard meds for Clinical depression—SSRIs such as Prozac and Lexipro—are like poison for the bipolar brain. Now picture the psychiatrist who is convinced that what you have is "regular" depression. He prescribes you the poison meds and sends you off. Only to find you sicker the next time you come to his office. "More depressed," he thinks, "let's up your dosage of the SSRIs." It's a vicious cycle that could leave you psychotic, psych warded, electric shocked, suicidal or worse.

Lucky for me, the fifth—yes fifth—psychiatrist I found when I was hanging to this life by a thread, Dr. P, is an expert on the Bipolar Spectrum. During my first appointment, he gave me a bipolar diagnostic test, a simple 14-question protocol. With this tool, it took all of 20 minutes to diagnose what had eluded the medical world for a quarter-century. "We know what to do," Dr. P said.

Dr. P was unequivocal in his diagnosis that I had bipolar II. This form of bipolar disease doesn't manifest in mania—I never had the characteristic wild highs, shopping sprees, sex adventures. But it does show up in dark, persistent, debilitating depression. And because it shares the symptoms of typical depression—low mood, weight change, loss of memory, no joy in life—it is most often misdiagnosed as unipolar depression. Dr. P's clarity and the meds he prescribed, Lamictal and later Lithium, saved my life.

When I was mercifully on the other side of the crisis and able to reflect, I asked Dr. P—a six-footfour, white-haired gentleman—"How did you get right what so many others got wrong?"

"They chose to stop learning," he said. "I felt too much responsibility to my patients to do that—it's about life and death. I kept studying. Still do."

In his December 2020 column "The Hidden Fourth Wave of the Pandemic," New York Times columnist Farhad Manjoo writing about the stress impacts of COVID-19 says, "America hasn't begun to face this year's mental health crisis." I believe he's right, and by the time this article is published, sadly, thousands, if not millions of more people will be in breakdown. For those experiencing mental challenges—and who isn't at this point—I want to offer some of what I've learned. If condensing 40 years of wrestling with bipolar II down to a fivepoint plan seems reductionist, it is. But this is meant to be a triage intervention to "stop the bleeding" in a moment of crisis. It goes like this:

#### Before the Crisis:

Identify a "Brain Buddy." This is someone you trust fully and loves you no matter what. Contract with your Brain Buddy that when you are in crisis you will text them "Code Red." This means that they'll call you immediately.

With your Brain Buddy or other friend or professional's help, create an affirmation for yourself that you will repeat on a regular basis. The affirmation is stated in the first person, present tense, and with feeling. For example, "I am safe, free, and loved." Or "I have a unique and beautiful brain." Or "I am loving, strong, and innocent." You get the point. The important thing is that the affirmation rings true for you and gives you a sense of calm and joy.

#### During the Crisis, Five Steps:

1) Notice what's happening in your body/emotions and give it a name that you state out loud. For example, "Self-judgement is arising." "Comparing-mind is arising." "Fear is arising." The key point here is that by stating the uncomfortable feeling as "arising" we separate it from ourselves and see it for what it is, a temporary

- state of mind. It does not own or define us. This works because it is simple and accessible in a moment of crisis. (You can learn more through the UMass Memorial Center for Mindfulness.)
- 2) When you state, "Fear (or other) is arising" that's your trigger to text your Brain Buddy, "Code Red."
- 3) Brain Buddy calls you and states your affirmation with you out loud, slowly, several times. This calms your nervous system and lets you know you are not alone.
- 4) Make a plan with your Brain Buddy for immediate next steps to get through the acute crisis.
- 5) Exhale and celebrate yourself for implementing the triage plan.

About that last step, celebration. Society still errs on the side of condemning those of us with mental health challenges as less than worthy. I am very intentional about my semantics here. You are not your "mental illness." You are not bipolar. You do have a bipolar brain. In other words, don't put an equals sign between you and your diagnosis.

I've recently completed a memoir about all this called BrainStorm: From Broken to Blessed on the Bipolar Spectrum. (You can find it here https://saraschley.com/saras-books/brainstorm/.) As I was putting the finishing touches on the manuscript, I found myself in doubt. Was it safe to "come out" of the bipolar closet and risk the judgment of others? At this point, my brilliant editor gave me the assignment to write this, "I am bipolar and a better person because of it." Through that writing, I finally discovered the freedom and pride to say "yes" to telling you my story.

The disease that almost robbed me of my life has also blessed me. My bipolar II brain has made me a better person. I am not saying that to be a Pollyanna. It took me 250 pages of a memoir to describe the sheer brutality of living with a broken brain, the demon that stalks hour by hour, the sadistic torturer who used to govern my nights and make my days feel like a bottomless Hell.

In some ways, having bipolar II is like being a warrior. Some soldiers don't come back. Others return with Post Traumatic Stress that they will never recover from. Some imagine suicide, and tragically many go through with it. But then some emerge from the horror and brutality of their experience with a new layer of depth and compassion and

sense of service. These are the survivors, the ones who can counsel those who suffer as they have. Because in their bones, in their cells, they know what that feels like. They've been there. They can serve.

This is what it feels like for me. I am a veteran of my own internal wars, a survivor of inner trauma. I bear the wounds of battle. I am grateful to be alive to tell the tale.

Bipolar II has made me a better person. It has taught me fearlessness, gratitude, discipline, and compassion and the ability to share all of these with you.

#### **Emotional Fearlessness**

There is no place your fears can take you that I have not been. I am fluent with the darkness and will meet you there. No matter how scary that place might be for you, it is not for me. I am an able partner and guide. I will accompany you on your journey.

#### Gratitude

Imagine you wake up every day with an excruciating, immobilizing headache. Your limbs are too heavy to raise you up from your bed. The winds are whipping, freezing, icy rain. You are cold, hungry and thirsty, but there is no food or water to be found. You are chilled to your core.

Now imagine all that lifts. Your headache gone. Your limbs loose and agile. Sun is out, balmy, gentle breeze. You have fresh ample water to drink. And organic greens from your garden to nourish you.

That's the difference I'm trying to describe. And what happens when you've emerged from that wind-whipping storm and into the bird-chirping spring? Gratitude in abundance. Gratitude like a flowing stream.

When colleagues have been surprised at my good cheer in these COVID times, I come out of the bipolar closet and explain how the pandemic is a walk in the park compared to what my brain has done to me. My brain free and clear? It's a glorious day. (I am mindful that this is colored by my extreme white-body privilege to live free and safe, with food and water and a family that I love.)

This gratitude, perhaps like the virus, seems to be highly contagious. And that's a good thing. An anti-depressant, a mood lifter, a force that re-orients us to the awe of creation. No wonder perhaps that so many spiritual practices begin the day with thanks. An abundance of gratitude born of bipolar II. Did I ever think I'd say "thank you" for that?

#### Discipline

If this was an AA meeting, , and I'm an alcoholic." Even if 40 years sober, it's still spoken in the present tense. That's how it is for me, "I'm Sara, and I have a bipolar II brain." I know—though it took me decades to accept—this is and will be true till the day I leave this planet. It takes a lot of work and discipline to keep my brain fit.

People who don't know my whole story will often remark, "You're so disciplined. How do you do it?"

"If you knew what was on the other side of this, you'd be too." There are diet disciplines and exercise disciplines and sleep hygiene disciplines and quality darkness and body working and mindfulness, and supplement and medication disciplines. (For rich and accessible discussion and guide to these health practices, see Dr. James Phelps' pscyheducation.org. An invaluable resource!) I do these with the vigilance of someone who has a healthy respect for what's at risk when my brain is out of chemical balance. Over the years, I believe I've learned to do this without the rigidity that was once there, but I am vigilant nonetheless.

How does this help me be a better leader? Well yes, leading by example. Whatever your challenge—physical, emotional, spiritual, I've probably got a tried and true and simple practice to help you transform it.

#### Compassion

There but for the grace of G-d go I. Absolutely. I will never judge someone sitting on the cold concrete in front of our local market with their homeless sign and cup out. I'm pretty sure they've got some variation on the brain I have. It's not their fault. Our US government is Neanderthal cruel in dealing with them. And if it hadn't been for my supportive family, health care, and good medicine, I could be right where they are. This goes for pretty much any addiction that leads to self-harm. I'm not going to judge.

I wish you strength, fortitude, and compassion as you move forward on your journey. There is no one like you in the Universe. From this moment on, may you be proud of your unique, powerful, beautiful brain.

Sara Schley is the author of *BrainStorm: From Broken to Blessed on the Bipolar Spectrum*.

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#### On Suicide and Survival

Anonymous Two

United States of America

Then my depressive symptoms began in early medical school, I noticed them more as a disconnect or distancing. As my energy drained, I found myself sleeping in, avoiding class, and catching up on the video recordings of lectures from my bed. When class attendance was required, I created an optimal route through my medical school building to get to a seat in the back of the lecture hall with the least chance of having to cross paths with my friends or acquaintances. I did seek out help from one of the school counselors, but I think I also hid the depth of my depression enough to not trigger any further treatment at the time. "It's not that bad," I'd tell myself. It's not like I needed to see a psychiatrist, or even worse, needed to go to the hospital. "I can get through this on my own," I tried to believe.

One and a half years later, during my clinical rotations, I finally hit a wall that showed me I couldn't do this on my own anymore. I can remember the day more clearly than most days during that period of time. It was my first day on the obstetrics and gynecology rotation. There was only one delivery by Caesarean section scheduled and the OB warned me, the fetus had died in the womb, so the delivery could be emotionally

traumatic. He offered the opportunity to sit the procedure out given the sensitive nature of it, but I felt that I had a responsibility to learn no matter how sad the circumstances. After all, medicine isn't without loss and grief, so why not deal with it now? I helped retract during the surgery and remember feeling surprised by the warmth of the blood that spilled out over my gloved hands. The warmth jolted me into realizing this patient, this woman on the OR table, was a living human being, even if her baby wasn't anymore. But instead of feeling the overwhelming sadness for her loss that I imagined I should feel, I felt nothing. I just felt numb. That's the moment I really realized something was terribly wrong in my brain. I went home and went to bed. The next morning, my body felt like lead and I literally could not summon the energy or motivation to get myself out of bed. I called my medical school and asked to take a medical leave of absence. I called my primary care physician and asked for a referral to a psychiatrist. I knew it had gotten bad, but I couldn't have imagined it would take me two full years to get back to my life as a medical student.

Ten months later, after multiple failed medication trials, I found myself fighting against thoughts of suicide. For many months now, I had had intrusive thoughts of wanting to be dead. I had methodically gone over ways to end my life, ruling out different options for different reasons. I remember one day clearly thinking about cutting my wrists, but not having the energy to walk down the stairs to the kitchen to get a knife. The thought of using a gun was the most pervasive. Thankfully, I was protected from that, given the lack of access or knowledge about using a firearm. Then, after months of struggling with these persistent and violent thoughts of suicide, I found myself counting out tablets of painkillers to see if I had enough to kill myself. I thought I was not just ending my own pain of existing, but felt I would benefit my friends and family by freeing them of having to deal with my depressed self. Thankfully, some part of my survival instinct told me to tell my then-fiancé before I actually took the overdose. As he drove me to the hospital, the main feeling I experienced was a sense of shame that I had let the depression get this bad. Admitting that I needed psychiatric hospitalization felt like I had hit

rock bottom. I cried not because I was so depressed, but because I felt like I had failed.

The thing is, that hospitalization was the turning point in my battle with depression. First, I realized that I wasn't alone. Second, I felt safe. And lastly, I was put on an additional medication that finally addressed the specific problems my brain had been experiencing. Depression is a manifestation of multiple variables, from psychological to social to biochemical; thus, treatment is unique to each individual and sometimes takes time to find the right combination for that person. While it took another year before I was well enough to return to school, had I not gone in that day, I may never have gotten well enough to achieve my dream of being a doctor, or worse, I may not have survived.

The fight wasn't over, though. My internal battle with depression and the shame I had felt now moved out into the open as the gap in my medical education became a red flag on all of my applications for residency and fellowship. I was asked about the leave I took at most of my interviews, despite that being an 'illegal' question. Many mentors have warned me at different stages in my training never to disclose that my leave was due to mental illness, despite going into the field of psychiatry. I'm not comfortable with this sort of secret, and so, when asked, I shared. Reactions have ranged from appreciation and respect to outright dismissal. I learned which hospitals and departments were open to seeing me as a whole person, not impaired or vulnerable because of a mental illness, but rather as resilient and insightful because of my experience and recovery. I matched to my first choice for fellowship and got a job doing exactly the kind of practice I wanted straight out of training in an academic medical center. I get to teach students, residents, and fellows, as well as practice my sub-specialty of psychiatry clinically. I have felt nothing but supported by my department leadership and mentors.

As an attending psychiatrist, I share my story and perspective with my colleagues and trainees. It also informs my understanding of my patients and often leads to a deeper connection than I might have otherwise had. I believe talking about our experiences is one step towards lifting the cloud

that stigma brings down as a veil on mental illness and its treatment. For me, treatment has involved not just a combination of medications that address my specific biological dysfunction, but also weekly therapy with a person I've come to trust and respect. I also make sure to surround myself with support from friends and family. I have shared with those closest to me the early warning signs of my depression so that we can catch relapses early so that I can either increase my contact with my therapist or adjust my medications with my psychiatrist before things get too bad. Stories are powerful and important and the more we share, the more we learn that mental illness is not some sort of personal flaw but rather a treatable disease. I believe through such narratives, we can end the stigma that only amplifies the suffering, and most importantly, we can let people know that there is help and there is hope.

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#### **Behind the Iron Curtain of Duty**

Monica Gupta

India

iving in a conservative small town in northern India, my desire to join the medical profession with the utopian ideal to alleviate human suffering was fuelled by my missionary school background and the portrayal of doctors in movies. My selection in a premier medical school made me the darling of my mentors and teachers, who rightfully claimed some credit for my success.

My naiveté to believe in the divinity of this "noblest" of all professions modelled a path of selfless service that imperceptibly ingrained itself into my very being. Instead of the squeaky clean wards portrayed in the movies I had seen, and polished textbook segregation of diseases into chapters I had read, the complex, uncertain reality of multiple dimensions of human disease struck me like a bolt from the blue. Somewhat shellshocked, I went along a path of critical evaluation of the repertoire of symptoms, harmonizing it with investigations, balancing the evidence and confusion it created with the management goals, guidelines and protocols only to be obfuscated by patient (and caregiver) desires and financial restrictions. The variety of patients and volume of medical information put me to the test repeatedly. I matured quickly in this charged atmosphere of successful "outcomes," with a large slice of the pie being agony, despair, helplessness, and loss, a somewhat difficult piece to swallow. I rallied time and again as a soldier of this army of drifting professionals, constantly hiding my emotions and tears behind the iron curtain of duty.

The profession of medicine extols us to strive for a nebulous virtue of a "good" doctor, a Dr. Jekyll, and I followed this to the hilt. Armed with a specialization in Internal Medicine and attempting to emulate what I perceived was the poise of William Osler and modern day evidence-based medicine, I fell in love with my role of "controlling" the fates of the myriad of patients who passed in and out of my life. The time schedules, night shifts, and the constant drive for perfection led me slowly and inexorably along a beaten path well-trodden by many others before me. I assumed myself indispensable, multitasking adequately so as to be 'good' in every aspect. Unsurprisingly, worry intruded into my life and soon became a habitual companion! My internal critic would often nag and rebuke me for my shortcomings. My constant preoccupation with analysing, judging and catastrophizing ultimately culminated in an awful panic attack five years back. I still remember that Saturday evening—it was weird.

It started like a subtle tremor building up to earthquake intensity, throwing me into a bottomless pit like Alice in Wonderland. The mild heartburn and palpitation attributed to a bad cup of coffee, a streaming rivulet of sweat across my face, an inability to breathe fully, and it appeared just as the commonly tossed phrase in our ER "impending doom." I could only describe it in Hemingway's beautiful prose "Because, just then, death had come and rested its head on the foot of the cot and he could smell its breath."

It was strange! All my knowledge, my medical education was floored that day. I wondered how an audacious and strong person like me could succumb. What! Me a nervous wreck! I wondered if I was really ever educated to handle myself, my emotions, my feelings, let alone handle the whole world.

I felt defeated.

After a while, my real trauma began. Was I puzzled, exhausted or dizzy? Was it PSVT? We talk so much of the dizzy patient and the algorithm springs to mind. Was it palpitation? We ask students to "define palpitation" as if the whole mystery of medicine lies within this profound statement. My friends offered kerbside consults "Breathe slowly," "Control yourself," "You're tough," "Keep your chin up," "You can handle it," "Take an anxiolytic," "Are you asthmatic? No, take a beta-blocker," but the worst was to be told to breathe into a paper bag.

The spouse appeared from nowhere and gently whisked me away. I recovered from this episode soon, but this led to another chain of events. Harrison's kicked in "Is it!" the endless list topped by phaeochromocytoma and myocardial ischemia. I was puzzled. My left-sided brain was hijacked! I contemplated for hours. I was full of 'What-Ifs'! I would get overwhelmed with a flood of negative thoughts running like a chain reaction terminating in 2-3 anxiety attacks on a weekly basis. Irrational worry had created a smokescreen through which nothing seemed real. I shuddered at the thought of sickness, death, and loss of loved ones. I developed irregularities in my heart rhythm that worsened my flail mental processes. I was going through a living hell.

The medical record entries of troponin negative, ECG non-specific, Holter records, echocardiography normal (not even Mitral valve prolapse?) followed. Here I was at the final frontier staring at the bright lights of a catheterization suite waiting

to be diagnosed. The thankfully short radial artery access angiography turned out to be normal with my cardiologist friend in the background laughing that the arteries were thick as swollen fingers.

Now began the next phase, as they say, "what happened?". Here I was, a successful doctor with a lovely family, two adoring kids and doting parents, and the best work-place in a beautiful small city, beginning a road to self-discovery. Somehow the doctor-patient issue had got twisted and become a doctor-patient complex, and the patient took up residence in the doctor only to break free and create chaos in my mind. I had chosen a path of letting my ideals and morals overshadow the rationality in real life. My desire for perfection, overzealousness, hair-splitting deductions, and constant wearing of a coat of armour against criticism in the clinical environment had made me-the patient-lay to rest the doctor in me.

My road to recovery was strewn with a heavy dose of religion, self-help books, meditation, yoga, chants, YouTube discourses and adequate anxiolytics as toppings. Time and providence, as they say, are great healers. From the haze that is reminiscent of Scarlett O'Hara's search in her "It's always hidden in the mist" nightmare, two friends emerged like pillars of the Pantheon, gently goading me towards the shores of stability. They helped me stand back on my shaky legs. Their non-judgmental approach, perseverance, and constant assistance helped me regain my lost world. They helped me defocus from physical symptoms and stop the traffic of thoughts. Luckily I withstood my life's storm with courage and my spark returned. My 'what-if's' have got swapped with a 'so-what' attitude. Life has turned out better than I ever imagined.

I have finally emerged a stronger, more confident member of the health care team, learning to absorb the emotional baggage like a sponge only to release it in the sink before it contaminates my mind. Switching off the Walkman during long walks on winding roads taking in the sights of nature, listening to the chirping of birds and animated chatter of beautiful souls whom I did not know have become my off-duty passions from which I continue to derive rich dividends.

Probably, I did not realize that by being an overconscientious child fed with good moral values, I had gradually let my superego and my conscience drive me to the point of over-empathizing, overcommitment, emotional overloading, and mental exhaustion. After being on the emotional roller coaster ride for nearly seven odd years now, I have finally realized the power of surrender; surrendering to the universe to channelize my path as it does for the billion humans on this earth who are alive. I have realized the power of self-care and self-love, which is above all duty and obligation.

I want to tell all you young doctors out there that any compassion is incomplete if it does not include you. This worthwhile adventure helped me gain wisdom that I couldn't have acquired in my entire medical career. It's like doing another post-graduation on cultivating courage and tuning into abundance. Embracing my fears has helped me develop a repressed emotional quotient. No doubt there are many bumps on this road to self-discovery and self-realization, but I am confident that I will pass my second education well.

I know being empathetic and supersensitive is my second nature, but now I can face these feelings more calmly. I feel empowered, liberated, and more alive. Now faith and happiness are my steady companions. I am celebrating my newly gained tenacity and resilience. I'll end my story with another quote that has helped me immensely 'It is impossible to live without failing at something, unless you have lived so cautiously that you might as well not have lived at all, in which case you have failed by default'- J K Rowling

#### **Double Life**

Samantha René Merriwether

United States of America

The hardest part of having a mental illness is not the struggle of dealing with the treatment, which is no easy feat, but it is hiding all of the symptoms associated with them. They are invisible to the outside world and on the inside, they pull you in a million directions. Those with a mental illness spend time making up reasons for why we cannot attend family and social events, go to lunch with coworkers or take a vacation with friends. Just as you must fight to keep together on the outside; you must equally fight to feel authentic on the inside. This essentially leaves you living a double life.

Since the age of three, I have struggled with mental illnesses; all were ignored because my family's focus was on how I looked. I was taught to only worry about the outside. And so, I did. I hid the abuse I was experiencing and instead I developed an eating disorder, which today is classified as Anorexia Nervosa; which has severely impacted my physical development and adult life. Since I grew up in a family where I was to be seen and not heard, the abuse I experienced turned into post-traumatic stress disorder (PTSD). These compressed by additional diagnosis' including Obsessive Compulsive Disorder (OCD), Anxiety, Insomnia, and Depression; ingrained a footprint on my childhood and continues today. There are nine mental illnesses I suffer from, all limiting my daily activities.

However, as an adult, just as a child, I hate the labels that I have been given and try to hide them at all costs. I wanted to fit in with my peers and hide all of the scars on the inside and outside growing up and nothing has changed. Perhaps the only difference is that I intellectually understand that what I went through growing up was not the norm. In some ways that makes me feel stronger for knowing that I survived what most people cannot but, it also once again puts me in another category to overcome. In addition, what gets me down is how our society is formed. Why physical appearance continues to matter more than anything else still fathoms me, however, it needs to be addressed. Too much of our lives is about what is on the outside: what we look like or what we wear. What is lost is whether or not individuals have disabilities on the inside. What is on the outside does not keep our society running. Nothing matters more than what is on the inside including our mental health.

Often, outsiders assume how mental illness' affects everyone based on the broad definitions of

these diseases; and what I am here to empathically express is that there is no such thing as a typical presentation of any mental illness. When in reality, just as in trying to treat cancer, there may be general guidelines and previous experiences that people can learn from but in the end one treatment is not going to exactly work for the next person. This is one part of being the patient that is stressful. It adds to my anxiety because I am not the typical teenager with bones sticking out of my body. I do not fit the mold and neither does my treatment team. Unlike many, I am ahead in my treatment because I know the root causes of my mental illness'. However, it does not erase my PTSD.

The abject environment I grew up in was a smoke screen to anyone who was not living in my home. It greatly distorted how and the way I function today. I have always been different and I knew as a kid that I did not fit in; and this was not just because I did not have friends or because I was overweight. There was something deep inside of me that limited my self-esteem and social interactions. I remember adults whispering around me, attempting to mask their opinions about what was wrong with me. The result of having more "labels" isolated me even more.

I have never been a fan of doctors because I grew up being poked as prodded all the while trying to figure out why I was not the perfect child my family expected. I was overweight and a sad child. I was perfect until I was two and then somehow a flip had switched and I was no longer a child any parent would apparently want. For me being so young and having been told that I was not good enough left me isolated and always afraid of my next move.

Of all of the scars I have, these are the ones that have the greatest impact on me; not to say that the physical ones have not left scars as well. Having mental illnesses come with a type of stigmatism that only those in the thick of it truly understand. It is an everyday fight and one I struggle with alone. Yes, I may have doctors to help but the day to day frustrations and isolation is what I deal with on my own. Most of the time, I do not want to be a part of society anymore. I am content staying alone and keeping my problems to myself. Why? Because getting other people down about something that

happened to me is not going to solve my problems. This is the cycle of depression that keeps me and many others out of the spotlight.

I wish that I could convey the frustration I feel of what being sick all the time is like. The best way I can describe it is like having a huge blanket that floats right over my head all the time and keeps me from seeing more than a few feet in front of me. What that means is that my life has to be very well structured with doctors and medications so that I can keep going. I have a food schedule that tells me when and what to eat because otherwise I would not choose to eat near as much as I do. I recently, and with a lot of hesitation, started medication to help with the depression. It is not working and making me feel even more of a failure because I again, am not fitting the mold. Typical treatment that works for most is not working for me. I should not be surprised by this but I am. I would like for once to fit in and not have to fight as hard as I do.

For those experiencing mental illness, one of the most important bits of advice that I can give is not to ignore that nagging feeling you have inside that is telling you that something is wrong. It is okay to color outside the lines, be your own person, and remember that all feelings are okay, regardless of what they are. But it is critical to get help in any way you are comfortable with. Getting help means going outside of your comfort zone a little but not so much that it causes more problems. Currently our mental health system is set up to put people in boxes and label them, which makes it even harder to get help. It is limited by how you fit in the box and what type of treatment you qualify for in conjuction with your insurance.

I would not want anyone to go through what I have but the one thing I wish for someone in my place is to have a safe person to lean on. Not everyone has access to the resources to treatment, which is often not fully covered by insurance and is even more limited by those who are on Medicare and Medi-Cal. This is further compounded by the fact that not every mental illness has the same number of treatment centers and specialists as others. But having someone that you trust enough to express your true feelings with is a mandatory component of achieving some relief.

I know there is no magic wand to make mental illnesses go away; I am not that naive. But I also know that the more time and research will go into relieving the pressures behind the causes of depression, eating disorders, anxiety, will help to save millions of lives. Traditional treatment options do not work for everyone and this means that it will take just as much courage to help those in need as it does for someone to stand up and say "Something is wrong and I need help." Even if you have been struggling for years, I do not believe it is ever too late to start getting treatment. I just believe that having a double life, even if it has been for decades, means that you will have to work that much harder at being your own advocate and learning new ways of coping.



#### **Second Chances for Bipolar Women:** Coming Out of the Dark, a Life Under Construction

Imelda Caravaca Ferrer

#### The Philippines

I am from a city up North in Metro Manila where I was born. Shiny, mirror-like floors where I can see reflections of me. A kitchen full of lovely cooking smells wafting up to my nose. And a table laden with milk, sunny-side up eggs, bacon and pancakes paired with maple syrup. Hand in hand with my cute brother who I defended on two occasions from bullies. I am from two souls who quarrelled a lot because of jealousy when I was so much younger. I am from a family that was torn apart only to get back together when I was in my teens this time in the province. I never talked about my father, that's what my classmates observed so they knew things

weren't right in my family. I am from a wooden house with rickety stairs. My nose tinged with soot because of the kerosene lamps we used at night. We dined on noodles and dried fish with ferocious regularity until the day my mother cooked sinigang and I innocently said: "Ï thought sinigang was only available in Manila." I am from a public high school where I could not do what my classmates did like hang out, visit and dine at each other's houses, my nose stuck on romance novels, my dolls I played with until second year high. I am from a university in another city taking up a course because it had few prerequisite math subjects which I hate to this day and if my life depended on it, I will surely die. I am from a city where when I got tired of being alone, fell in love. We ended up marrying and after 7 years it ended. My gifts? Two young boys who I love with every breath and sinew of my body to the heavenly constellation and back. I am from a land where good men are not a-plenty (Or maybe I have yet to meet them.) I am from a land of dreams, musical chimes and poems that do not rhyme, where my words are kites that bob jauntily or nose-dive sadly whatever the mood is. And where my romantic desires

are visible to anyone who cares enough to really look and my unspoken prayers are heard by my God who I resent at times. I am from a land where certain people talk behind my back, belittle my dreams, snigger at my being yet I soar above and leave them where they bite and choke on the dust of my wake. I am from a land of promise, of endless, infinite possibilities where I am loved. And as sure are the plans of the Lord has for me, though I may not see them yet, I know I will make it! May 25, 2017/Thursday/2:06 a.m

n 1980, I was a freshman at University. My aunt loved me but she was also the one who **L**stripped me of my self-esteem and self-worth because she called me "Batangaw" or "Bad breath" because we were so poor and my dental health was not given attention.

I recall attending a regional seminar and I was taunted for having bad breath. I was given a bouquet of bad-smelling flowers. I was shattered, devastated. I started hearing voices.

My cousin who was pregnant and nearing her term, God bless her kindness, brought me to the National Center for Mental Health. I was initially diagnosed as Schizophrenic. I didn't realize, didn't understand that I was to take meds for the rest of my life. After a summer of sleeping my depression away, and salivating because of Haloperidol, I went back to the province to resume my studies. But the voices, loud voices of men taunting me persisted.

For two decades, even as a first time teacher until I was 40 or 41, everything came to a head. My mom died and I finally saw the psychiatrist of a friend. Fluphenazine decanoate was given to me as an injection. The voices stopped.

I also sought consultation at an outpatient department. They told me that I'm too functional to be Schizophrenic. So they said I'm Bipolar.

I have a support group. I have a psychiatrist. I have a life coach. I have a spiritual family that I belong to. Counselling helplines are at my disposal. I attend retreats regularly. I send prayer requests to international prayer websites regularly. I journal. I'm a writer. I'm currently finishing my memoir, "Second Chances for Bipolar Women: Coming out of the Dark, A Life Under Construction."

I've several wins under my belt—a former award-winning School Paper Adviser, a graduate of the top state university in the country. I'm a published textbook writer, a national trainer, a former public schools principal, a former Editor-in Chief of our official newsletter, and currently a Public Schools District Supervisor. I've self-published my poetry book earlier this year and will publish my memoir on Amazon, hopefully, in two month's time.

I came from a broken family. I experienced extreme poverty, and was molested by the people who were supposed to give me love and care. I never had a voice. My mother left my father. We lived in the province, then when we were teenagers, he was back with us. No explanations at all. I got married, cheated upon, then got separated. I became a single parent.

I have a skewed definition of kindness. It usually involves me shelling out money, buying stuff, lending money because I attract needy people. I wanted to be called kind. I wanted to matter, I wanted to be validated. I wanted to be called loving, generous, and giving because of my underlying motives, needs and desires: I wanted to be loved in return. But that didn't happen. I was abused for my kindness.

Being separated for 24 years has dented my love tank. I want affection, intimacy, one that is beyond simply sex. A priest I confessed to—he saw me for the first time and he said this: "You have a very big heart and people have a tendency to abuse you."

I just had those a-ha moments with much help from God when I had a session with my life coach yesterday evening.

Now, I'm wary. I don't want to help people anymore. I've reached my quota. I just want to help my

family and myself. I don't have to be shelling out money just to be considered kind. I am kind because I don't take advantage of people. I'm innately good because I pray for all people. I listen well to others. I give good advice. I'm intelligent, funny and fun to be with, and when I give talks, they tell me that I'm inspirational.

I'm most Bipolar when it comes to my expenses. I'm drowning in debt. And that's not helpful.

People talk about me because I'm not the usual Supervisor—I'm authentic, raw, in fact, too honest for my own good. I cosplay and have spearheaded spoken word activities. I am a member of Hogwarts Philippines. I simply love giving training sessions on teaching reading. And people are afraid of things and people they don't understand.

Last month, I attended a 30-day transformational journey where I and the other participants would listen to helpful video talks, listen to forgiveness prayers and as for me, I keep going back to the healing the little girl in me activity. I will continue writing on my self-love journal. I will continue listening to meditations, podcasts of Pastor Joel Osteen of Lakewood Church, and that also of Boiling Waters Philippines because they give nifty advice on relationships.

This year, I've fallen in and out of love. First with somebody who ghosted me in 2019 and because of the hardships during this pandemic touched base with me in January 2021 and started borrowing money from me. It happened so fast that I just found myself in a relationship with him. Something that when I remember now, I shake my head. I used to be a hopeless romantic. Now I'm wide awake. He had a common-law wife and although we had plans to meet, it never materialized. My best friend said that if he was interested, he could have met with me a long time ago, "The entire family was fooling you. They're in it together."

Did I learn my lessons? Nope! I had a rebound relationship with a 22-year old guy who is married. My vocabulary grew with rebound relationship and NRL (No Relationship Labels). For almost a month, I experienced being the other woman, a scenario I never thought I'd be in. I spent sleepless nights, crying because he couldn't give the attention I was craving. He said he's controlling himself not to fall

for me. I couldn't do the same. Like the other guy, he also kept borrowing money from me. We met once and did the deed. His wife read my goodbye letter in his Whatsapp. He gave me more than his body. I asked my doctor-friend to give me an e-prescription because I seemed to have a UTI as my urinalysis test revealed. Then I said these damning words, "I have yellowish discharge."

My doctor-friend asked, "Did you have unprotected sex?"

"I'll answer you but not here on Messenger, my son reads my messages."

"Yes, I did," I texted my friend.

"Well, swing by the hospital now. You are sick."

So I rushed to the hospital, got my injections, which were truly painful and the lab results came out after a few hours—negative.

Whew! I don't have sex for long stretches of time and now this. Perhaps I'm meant for the convent after all.

**Breaking Free** 

I'm breaking free but let me take a moment.

I think you kinda know that there'll always be a part in both of us that will always care for each other.

You know I want the best for you and you want the same for me.

The memories, the fragments, the colors will slowly fade.

But right now, you're all I think about.

I think I'll avoid the places that reminds me of you so I could recover.

Your unspoken words, my arid, empty heart.

I wish I could hate you, my baby.

My fingers will dance, hover over your number, try my best

not to call you to hear your voice for old time's sake.

I don't have to because in my mind I still hear you.

You know you got the best of me. I loved you so. Still do.

I pray to God that I'll get you out of my system.

I wish I really, really knew how you felt about me.

You tried to push me away by not giving me attention.

You tell me not to fall for you but it's a little too late for that.

Maybe you're holding back for both our sanity by being the voice of reason.

I know you feel something. Maybe you're even hurting a little, denying your feelings for me.

You know this love for you is real but I don't want to keep hanging on.

I'm fighting back my tears, trying to keep them at bay.

I'm moving on.

#### May 21, 2021/Friday/11:39 p.m./ Heightened GC

My other best friend who is a doctor told me to avoid young blue collar workers. A Facebook acquaintance chatted with me out of the blue telling me that he fell in love with me the first time he saw me.

He seems kind and has principles I admire but I'm out of his league. Not that I'm wearing a proud hat or demeanor. He's a promodizer at an outlet. He's 30 to my 58. I dunno why I attract these kind of men, maybe because I'm also needy?

My other friend also told me that I should entertain someone who is also like me—intelligent, has a good job, everything that these young men do not have.

I frequent a beauty spa. There's this guy who is bisexual and finds me to be kind. He told my friends that he could go for me.

I will stop frequenting that place to give my heart space. These 'boys' are just distractions. Although, I'm an impatient miss, I like to believe, God help my unbelief that God has his plans for me, plans for a hope and a future.

I'm annulled in church but not civilly so if I'll be a staunch Catholic through and through, I cannot entertain guys. The live-in partner of my ex-hubby has been dead for almost 2 years now. Since November of 2019, he has had four girlfriends already. I wish I didn't have scruples. I wish there were no double standards.

Now, I'm reclaiming lost ground. I stopped my usual regimen of praying, reading the Bible, attending the virtual masses of the Light of Jesus where I belong. I will try to keep busy, finish writing my memoir, try to read 10 pages of a book every day, for I'm a lapsed reader. I will save up for the AC review so I could take the exam and be a School's Division Superintendent. I will make sure that I get the money that I lent to people. It's important to adopt a positive mindset. I'll try my best to read my self-affirmations. This June, I'll be attending the Healing Summit for Women. I'll always ask for prayer requests from international prayer websites because they really help.

The advice I would give to someone with mental health challenges—know when to ask for help, have a group of friends who have your back, guard your heart, try a lot of things that will save your life but most of all—have a loving relationship with God. I'm a sinner. I stray from the narrow road but I find myself going back to God again and again. Now, I truly see the need to look back, ferret out from deep down, the roots why I behave like this and that. Indeed, awareness, is the greatest thing to acquire that will pave the way for changes.

I have a vision board I need to look at regularly and pray for, read the Runes, my prayers in my prayer book, strive for a closer relationship with God. It is not rocket science, but studies have

revealed the efficacy, the power of prayer in getting healed. So help me, God.

I will always write what I feel to process my feelings, journal, write poems and stories because writing will save my life. I am seriously accepting one of my roles in life—to be a great writer who will inspire and leave a legacy to my family, friends and future readers.

I am blessed to have many opportunities at my disposal and I share what I know. I pray for those who do not have the same opportunities.

## **Commentary**

# Reflecting on Global Challenges on the Way to Advancing Mental Healthcare

#### Dainius Pūras\*+

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**Abstract.** The 12 narratives included in this symposium on living with mental health challenges reflect the broad spectrum of experiences and interpretations of individuals who have mental health conditions. They also reflect the range of views within global mental health discourse about effective ways to improve the mental health of individuals and populations. Some important issues are common in these narratives, notably how experiencing trauma, particularly in childhood, can impact mental health. The narratives present a broad spectrum of views regarding the interpretation of mental health conditions and the ways mental healthcare systems have addressed them. These narratives demonstrate an urgent need globally to liberate the field of mental health from the overuse of the biomedical model and allow other models to compete and receive support.

Keywords. Global Mental Health, Biomedical Model, Narratives, Medical Ethics

"To those individuals who are struggling with any mental disorder, I would say that we are not just a diagnostic, a medication, or plain symptoms. We are humans and that should be our identity. With this, I mean to say that a diagnosis should not define what we are, or who we are. A diagnosis should not impose limits on our lives. If anything has been characteristic through my years is my reluctance to give up" (Armando, Puerto Rico)

#### Introduction

The 12 narratives reflect very well the broad spectrum of experiences and interpretation of individuals who have mental health conditions. Interestingly, they also reflect the range of views within global mental health discourse—when it comes to the question about what are effective ways to improve the mental health of individuals and populations.

These are very different stories, with different contexts and therefore, it is difficult to make general conclusions. However, there are some important issues common to all the narratives. All authors keep on struggling passionately for their lives and their happiness, and they do not give up as they face their mental health challenges. This resilience and empowerment may be constructive and therapeutic and provides insight: attempts with self-reflection and meaningful participation, even if they are painful and do not necessarily result in immediate

positive effects, in the long run may contribute to recovery.

The ability to reflect upon one's mental health condition may be a powerful protective and empowering factor, as it helps to avoid seeing the mental health issue only as a negative kind of "pathology." Instead, this can be seen as a unique experience that adds to life's meaning and to a higher level of resilience. For example, Natalya writes: "I've learned to be more tolerant, more patient, more compassionate, and thoughtful. I wouldn't be the person I am today without my anxiety and my depression".

When reading the narratives, I was mainly interested in how they reflect the competing views in the global mental health discourse about the best ways to invest in mental health and mental healthcare. I had a unique opportunity, as a UN Special rapporteur on the right to health (2014-2020), to explore in-depth opportunities for and challenges to realizing the right to mental health. Several of my reports to the UN specifically addressed the current situation in the field of global mental health and human rights.

My comments will therefore be mainly related to how these narratives reflect the current models of understanding and improving mental health, and how they contribute to the discourse around the present and future of global mental health.

As we know, there have been dramatic shifts of paradigm during the last centuries and decades in the field of mental health. Practices for supporting people with mental health conditions have been changing, as they were affected by prevailing theories and models within and beyond mental health care. First of all, the thinking about what causes mental health conditions has been changing since the 19th century in a pendulum-type way, moving from "mindless brain" to "brainless mind" and the other way around. When a person is not feeling well mentally for a long time, behaves in a way that other people think is abnormal, or attempts to commit suicide, many different theories have been developed to explain the cause of those conditions. These theories have been established from different fields of science (e.g., medicine, psychology, public

health), so they have resulted in varying curative practices.

But before we move to prevailing attempts to manage mental health conditions, I would like to elaborate on the fact that in many of the narratives, childhood trauma, adverse childhood experiences, and other effects from childhood are especially highlighted by the authors.

#### Childhood Experiences

In her narrative, Natalya from Bulgaria describes how she has experienced social phobia since her early childhood. When describing her family relationships, she writes that her father was "never one for a personal problem-related conversation," though she loves him deeply. She goes on to say:

"My mother, on the other side, is a typical example of an emotionally absent parent. Our relationship has always been cold at best. To this day, I cannot remember having a single meaningful conversation with her or having received a piece of wisdom I could use in life" (Natalya).

Konstantinos from Greece describes the abuse he suffered as a child.

"My parents were very violent against me, both physically and verbally. I accepted maltreatment during my childhood and my adolescent years. My father was cursing me, insulting me, hitting me at the first chance. During my adolescence, I found the courage to resist and defend myself." (Konstantinos)

Glenn from Canada lives with anxiety that he has experienced for most of his life. He writes:

My family did not have any understanding or compassion for what I was dealing with when it came to my mental health challenges . . . I had little confidence because my parents and family always told me I was not good enough and that I would not amount to anything. Because of this, I was never given an opportunity to go after my passion in life, which hurt my feelings and shattered my confidence" (Glenn).

And Armando from Puerto Rico describes this traumatic childhood experience:

"My mother took me to visit my grandparents' house. I was the youngest of three, my brothers stayed at our house, and I was left at my grandparents over the summer. That first night my granddad came to my room, pull the blanket off me, and started touching me, eventually leading to oral sex. This became an ongoing routine every time I stayed at their house during the summers and holidays for the next seven years. He would tell me that it was our secret game, and he made me promise not to tell anyone . . . Most of the time, I felt ashamed and embarrassed of what would go on during those visits, being unable to tell anyone."(Armando)

These are just some of the episodes from the narratives that illustrate painful childhood memories. All forms of violence against children are detrimental to mental health and well-being throughout the entire life span, especially as violence tends to become chronic. And it also includes all forms of neglect, such as emotional neglect, which can be very painful. Sadly, in many parts of the world, children still suffer from violence and from the hypocrisy of the adult world. While the Convention on the Rights of the Child and other international treaties protect children's rights to be free from all forms of violence, there are still many forces that justify and condone many forms of violence against children (United Nations & the Committee on the Rights of the Child, 2011). This is being done, for example, under the pretext of protection of "traditional family values" —an agenda that has recently become popular in many parts of the world

As will be discussed later in this commentary, the last four decades in global mental health have been dominated by the biomedical model. One of the effects of this model (and the fact that the biomedical model replaced the dominance of the psychodynamic approach) was that events of childhood and other life events were no longer considered to have an important role in the development of mental health conditions. Future psychiatrists were taught in many medical schools not to pay much attention to stories from mental health service users about what happened in their childhood. However, recent years have brought changes, and nowadays, adverse childhood experiences are considered again to be crucial to the development of different mental health conditions. First of all, child abuse—sexual, physical, and emotional—may have a detrimental and lifelong impact on mental health. This applies

not only to common mental health conditions (such as depression and anxiety), but so-called psychotic conditions (such as schizophrenia) may also be linked to negative childhood and adolescence experiences, especially to sexual abuse (The British Psychological Society & Division of Clinical Psychology, 2017).

Interestingly, progress in neurosciences has resulted in additional scientific evidence of the critical negative impact of toxic stress and adverse childhood experiences (ACE) on mental and physical health during the entire life span. Research on the development of the brain in early childhood has proved that healthy emotional relationships between baby and primary caregiver contribute effectively to the quality of brain architecture. In contrast, toxic stress (one effect of emotional neglect) has a detrimental impact on the quality and quantity of synaptic connections (Shonkoff et al., 2012). All these discoveries strongly support the modern understanding that all forms of violence and adverse childhood experiences and childhood have an enormous impact on the development of mental health conditions in adult life (Nelson et al., 2020).

#### Global Mental Health—Invest in the Status **Quo or Move Towards a Change** of Paradigm?

The narratives present a broad and thoughtprovoking spectrum of views regarding the interpretation of mental health conditions and the ways mental healthcare systems have addressed them.

In most stories, the authors describe and define their mental health conditions in the way they are presented in mental health services worldwide. International classification of diseases has several hundred diagnostic categories in the field of mental health, and management of mental disorders is based on diagnosing and then providing treatment according to approved treatment guidelines. As a rule, the authors speak about their mental disorders or illnesses, diagnosed by experts in psychiatry, and reflect on attempts—whether successful or not—to address these illnesses. This reflects what could be

called the "status quo" within global mental health during the last four decades.

The practice of mental healthcare, when based on the biomedical model and strongly focuses on psychiatric diagnosis (drawing parallels with other fields of medicine in this regard), has several significant advantages. We can trace these advantages in some of the stories when authors explain that messages from medical doctors brought more clarity and helped them understand their diagnosis. Bunna Phoeun from Cambodia did not know what schizoaffective disorder or mental illness was and explains, "The doctor told me that I had a mental problem (sa sai brasaeat)—that I have to take psychiatric medications." Bunna says before this, "I was shocked because I thought I just had a different personality from other people."

However, there may also be disadvantages or negative effects from the dominance of the medical model. Firstly, psychiatry is not an exact science, and I could bet that it never will be. Author Armando's example, which illustrates that a person could be diagnosed with different diagnostic categories with subsequent chaotic treatment changes, is not that unusual in mental healthcare nowadays. Armando writes:

I received several diagnoses that in turn resulted in changes to the medications I was taking. The doctor would change the diagnoses every other month from post-traumatic stress disorder, borderline personality, bipolar disorder, and general anxiety. This constant change and unstructured therapy made me skeptical and wary, missing a lot of appointments and medications. After nine months in medication therapy, in 2014, I attempted to commit suicide by overdose, something that would happen again a few months later" (Armando)

Focusing on a medical diagnosis and medical treatment based on that diagnosis can be meaningful and helpful to mental health service users. This is presented in current psychiatry textbooks and what is taught as of the beginning of the 2020s in medical schools globally. So we could stop the discussion here. But things are much more complicated than that, and the narratives reflect the rising tensions and make many hints about how complex the world of global mental health is.

The biomedical model (with a strong focus on diagnosis and medical treatment) is often used excessively and in a misleading way. Focus on medical diagnosis leads to the conclusion that the person should be receiving medical treatment. Again, this can be helpful, and we see in some stories that after some psychotic breakdowns, treatment with medications and hospitalization to the psychiatric inpatient unit was necessary. Bunna from Cambodia has learned, as a most important issue— "follow your doctor's instructions and take medicines regularly". However, as we can read from some other stories, this quite often is not enough.

A therapeutic relationship (alliance) appears to be crucial for mental health service users to trust the medical doctor. With the help of the alliance, patients have the trust they need to proceed to an effective recovery process. For different reasons, quite often, this kind of trusting relationship does not form.

Anonymous from Colombia seems to be disappointed with earlier relationships with doctors. They write, "Doctor Salvador was the first doctor connected with my suffering. I trusted him." This is not surprising because the interaction with doctors Anonymous has had before went like this:

Every session would last 15 minutes. She diagnosed me with chronic fatigue syndrome. 'it's nothing serious,' she told me. She prescribed Clonazepam and the Triazolam. In each appointment, she needed to increase the dose and add more medications to my prescriptions (Fluoxetine, Sertraline, Mirtazapine, Escitalpram). Still, she did not seem to care about my blackouts."

The effectiveness of therapeutic interventions in mental healthcare remains an area of intensive debate and disagreement. And the narratives reflect these differences in the views of experts—including experts with lived experiences

Logically, in most stories, medications are mentioned as the main treatment option. They may be helpful, and some authors confirm improvement when they use medications. However, in many cases, this may not be enough or not needed. Also, there may be cases when the focus on psychotropic medications to treat mental health challenges might not be a good solution. In other words, the

dominance of the biomedical model has not fulfilled what its representatives have promised—to contribute substantially to addressing stigma and discrimination. Ironically, many people in the world suffer from the effects of mental health services, unfriendly to their rights and needs, more than they suffer from natural causes from their mental health conditions.

One important issue in mental healthcare is the use of involuntary measures (coercion). Coercion has always been used and remains widely used in psychiatry. In many instances, involuntary placement and treatments are justified as "therapeutically necessary" or prevent the person from becoming a danger to themselves or others.

There is increasing pressure from different organizations and experts—based on evidence and on human rights arguments (especially after Convention on the Rights of Persons with Disabilities came into force)—that coercion is not acceptable in mental healthcare and should either be banned or substantially reduced (World Health Organization, 2019). This is a very delicate issue, dividing experts into opposing camps and creating a situation of impasse. Without going into more detail on the global situation, and going back to the narratives, some of the stories touch on the painful effects of involuntary measures on the self-esteem of users of services and on issues of therapeutic alliance.

Fehmida describes her experience of mental health service user: "I have been frightened, ridiculed, humiliated, coerced, victimized, abandoned, exploited, and made to feel invisible because of my mental illness."

Another touching episode is from Syrena, who describes how she was subjected to coercion after a situation in which she says the staff refused to let her use the phone.

"I was tackled and taken into a small room where I was pinned to the ground and injected with a needle in my butt. Within minutes I was knocked out by the sedative they gave me. When I finally awoke, I was terrified by my surroundings as I was locked up in a 12 by 8-foot room with a small barred window, a metal sink and toilet, and a small mat to lie on . . . I began to cry in desperation, begging them to hear me, to talk to me, but no one came . . . This experience brought on a lot of anxiety and shame as memories of

past trauma came flooding back to the surface. And although the staff had no way of knowing this about my background, they should never have taken such extreme measures to deal with my situation."

The fact that coercion and overuse of psychotropic medications are on the rise in all parts of the world is concerning. The UN Human Rights Council has issued three resolutions on mental health and human rights—the last one in 2020 (United Nations & the Human Rights Council, 2020). In these resolutions, governments are urged to address human rights violations as a matter of urgency, and first of all, to address coercion.

The question remains—what changes are needed to make things different? Psychiatry has a longstanding history of coercive measures, and many experts still hold the opinion that this is unavoidable. The De Bry Family's story, "On the Road to Get Our Son Cured From Schizophrenia," is a very illustrative one and shows that things can be done differently. The story reflects the depth of the problem with the biomedical model and demonstrates the need for competing approaches. The De Bry's story is about Valère —a young adult diagnosed with schizophrenia, and the parent's initial disappointment in how Valère's mental health condition is managed. After travels to many countries in all regions, I can confirm that such disappointment of persons diagnosed with schizophrenia and their relatives is very common nowadays. In Belgium (where Valère is living), there are more opportunities for diverse services than those offered in many other countries. And still, the prevailing pattern in all countries—both developed and developing ones—is that there are expectations by mental health systems and their managers that biomedical interventions—mainly treatment with psychotropic medications—is the best solution. This is a wrong belief. In fact, psychotropic medications might be needed for some patients, but just focusing on medications will never lead to recovery.

There is an urgent need globally to liberate the field of mental health from overuse of the biomedical model and allow other models to compete and receive support from governments that are funding mental healthcare systems. The "Open Dialogue"

model, presented in one of the narratives, is one of the so-called "alternatives." And there are many more. In June 2021, the WHO launched the Guidance on community mental health services, which strongly supports the need to move towards person-centered and rights-based approaches (World Health Organization, 2021).

This is why the global community needs a new paradigm shift in mental health policies and services. Instead of strongly focusing on how to "fix mental disorders" by targeting individuals and their brains, we should address the quality of the patient-provider relationship and the social determinants of mental health. This is what a human rights-based approach is about, and this is why governments are urged now to invest in mental health services that are rights-based.

There are no simple solutions to the questions raised about important issues related to the present and future of global mental health. With the passion and wisdom of the contributors, these narratives contribute to needed discourse. They signal that there will always remain different views and different avenues on the way to making the lives of people who struggle with mental health challenges of better quality, dignified, and meaningful.

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## **Commentary**

# We Need Warp Speed Attention to Mental Health Challenges Around the World Right Now

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**Abstract.** People from all over the globe told their stories of living with mental health challenges. These twelve people had numerous commonalities and reflected on a number of salient themes and lessons for those of us in the mental health field as well as those with lived experience. These lessons are especially important since we have been experiencing a global pandemic, which has exposed an urgent need to understand comorbid conditions including mental health. It has also highlighted the importance of diversity, accurate scientific communication and kindness to one another. Important lessons I learned reading this collection of short stories are organized into these topics: a) words matter; b) it should not take a pandemic to realize that people are living with mental health challenges and they need our help now; c) there are more similarities than differences in the world; d) trustworthiness is foundational to wellness; e) people with mental health challenges need to be heard, and, f) love is a powerful fixer.

Keywords. Lived Experience, Depression, Anxiety, Health Equity, Mental Health Disorders, Narratives

The 12 stories of people living with mental health challenges had numerous commonalities and reflected a number of salient themes and lessons important for mental health professionals as well as those with lived experience. These lessons are especially important since we have been experiencing a global pandemic, which has exposed an urgent need to appreciate diversity, comorbid

conditions, including mental health, accurate communication of scientific findings and showing one another kindness and love. Krishnamoorthy et al. (2020) noted that the burden of mental health problems seems to have risen due to COVID-19, with nearly half of community-dwelling people around the world reporting this as a significant consequence of the virus. Sleep conditions followed

by generic stress and distress were among the most commonly reported problems.

Stratification of the populations found that patients with COVID-19 had the highest burden, followed by health care workers and the general population (Krishnamoorthy et al., 2020). That systematic review of studies was an early indicator of mental health treatment needs from a global perspective. Further, this burden has been over and above the already high rates of mental health disorders reported, such as depression and anxiety. Being mindful of the prevalence of mental health, neurological and substance use disorders is especially important now when access to medical care, treatments and prevention interventions is necessary to improve quality of life (Charlson et al., 2016).

That brief introduction is a lead in to this commentary, which characterizes the important lessons I learned reading this collection of short stories. My thoughts are organized into these topics: a) words matter; b) it should not take a pandemic to realize that people are living with mental health challenges and they need our help now; c) there are more similarities than differences in the world: d) trustworthiness is foundational to wellness; e) people with mental health challenges need to be heard, and, f) love is a powerful fixer.

#### Words Matter

The writers of all stories shared their feelings, their challenges, their diagnoses, and their treatments. As someone who has worked on the development of the International Classification of Diseases and the Diagnostic and Statistical Manual of Mental Disorders (nomenclatures that the world uses to diagnose symptoms of mental health disorders), I found the words the authors used to describe their feelings and behaviors to be more illustrative and clarifying than some in these official nomenclatures. I found their descriptors to be authentic; I also found it somewhat frustrating because the expressions used by people with lived experience in these stories have not been included in the descriptors for the criteria or in the elaborations of the criteria in the text of the nomenclatures.

The authors of these stories described "profound emptiness inside/intense sadness" and "being tired of living;" they said "all energy had been drained," or that they had "existential fatigue," or "a feeling that things that used to give pleasure were mere burdens." People with paranoia described their symptoms of hallucinations as a "war stirring up people" or "needing to withdraw money from a bank and keeping it with me" or hearing the "sound" of cooking; they described "seeing fingers reach out" to them. People with mania described feeling a combination of "both poles," "a horrible nothingness, darkness, and pain" and even "profound, even transcendent, beauty and meaning in suffering."

This led me to the first lesson—that words matter. They are the language used to provide medical providers with diagnostic concepts that can be used around the world to describe human behavior. They allow people in Cambodia, Bulgaria, Canada, Australia, and all other countries to have a unified definition of depression, mania, bipolar disorder, schizophrenia, and other disorders. Our knowledge of mental health challenges among people from Cambodia, Bulgaria, and countries remote to the US has been sparse because not as much attention has been paid to understanding mental health needs there compared to the US and other high-income countries. This means that we are farther behind in planning for treatment needs and programs in those areas.

While words are an important aspect of epidemiologic research and facilitate understanding of the risk factors and patterns of symptoms that comprise a disorder, they can also connote a negative feeling or may stigmatize or label people. Some of the words and phrases discussed in the stories were idiomatic expressions, and would never make it through the final editing process of a diagnostic manual, not only because they are not universal, but because many of the terms are pejorative. These words have been passed down from generation to generation to describe people with certain conditions and are commonly used phrases. Examples of such words are: a nutter (from Bulgaria), psychopath (from Cambodia), a dark and cold shadow (from Colombia), or a mad person (from India).

While providers did not use these words, they did, according to the authors, attach their own words to these conditions. Several authors said that when they were actually given a diagnosis such as bipolar or borderline personality, they felt relieved since their doctor had now sufficiently found a word that meant "abnormal" or "mentally ill," which could be coded in their medical charts and would then allow for adequate treatment such as medications to be prescribed. On the other hand, Visnegarwala described feeling "invisible" and said that her opinions did not matter once she received a mental illness diagnosis. One author commented that these "words" are necessary for healing. Others said, in so many words, we are not our diagnosis. "We are humans," and one's diagnosis does not define us. Nair-Collins challenged that refrain, as did Nataliya Yaneva, who said she wouldn't be the person she is today without her anxiety and depression. O'Brien wanted people to know that she is human and that people should see her fragility so that they see that mental illness is a normal human condition.

Our job as researchers in this field is to conduct research that matters, that can remove the stigma, and that can provide the most appropriate interventions at the most appropriate time. Our job as providers is to use words accurately to explain a patient's condition and realize that some words may stigmatize people. As Norman Sartorius stated, "doing nothing about stigma and the discrimination that follows is no longer an acceptable option" (Sartorius, 2009). This leads to the next topic.

# It Should Not Take a Pandemic to Realize That People Are Living With Mental Health **Challenges and They Need Our Help Now**

The COVID-19 pandemic has highlighted multiple epidemics such as hypertension, diabetes, poverty, mental health challenges, and systemic racism (Grumbach et al., 2021). Just as systemic racism is embedded into the lack of health care access, so is systemic stigma related to mental illness. The pandemic has definitely shone a spotlight on the need for mental health and wellness. While the world

is more aware of mental health challenges, it is not more able to facilitate treatment for those who need it. People the world over have an opportunity right now to step up and advocate for people with mental illness.

One story described how everyone needed knowledge about mental health so that everyone could understand what people were going through. Roil stated that mental health has affected his entire well-being and that he has "felt less than a person on some days." But, as also mentioned, with the knowledge must come action, which means our academic health centers and health care providers support those living with mental health challenges, as well as their families and caregivers.

The pandemic has been a wake-up call to require new ways of thinking about delivering care, providing more access, and how we can support those who need us most. While this time has woken us up, we should have been more willing to listen and made mental health and wellness more of a priority. People with mental health challenges should be involved in decisions about treatments, interventions, and regulations all over the world so that the treatments, interventions, and regulations are person-centered and relevant to those living with these very issues.

# There Are More Similarities Than Differences in the World

Each person remarked on a feeling or complaint about, a solution to, or a description of their illness that was similar to another's—no matter where they lived or grew up. Having traveled to many countries around the world, I can certainly understand and have often commented on how there are more similarities than differences across the globe. Mental illness has no borders, yet treatments and interventions do. The same treatments in high-income countries are not always available to people living in low-income countries; that was discussed in several of the stories. One reason for this is the scarcity of resources, from medications to interventions to people in the workforce who can diagnose and treat individuals. However, the disorder and condition

are, for the most part, similar the world over with a few exceptions such as those that are conditional (e.g., PTSD, substance use, and gambling-related) because exposures to traumatic events, substances, and gambling venues differ by region.

When there are differences in rates of mental illness, it may be because there is a true difference in prevalence due to some unknown reason, including comorbidity with other conditions, religious differences in exposure (substance use), and others. Another reason could be that each culture has its own way of describing illness, such as mentioned above, and the concept of illness is starkly different. There may be learned behavior about seeking help so that the illness is never brought to the attention of a particular clinic, or there are differences (such as age or gender) that are associated with help-seeking populations. Quiñones-Cruz mentioned a common refrain—seeking help required commitment, which meant following recommendations, engaging with the exercises, and being a full participant in therapy.

# Trustworthiness Is Foundational to Wellness.

Trustworthiness is the word of the year. No matter what the context, it is important and foundational. Human interactions involve trust—and this is foundational to the doctor-patient and support grouppatient relationship. Patients and families need to be sure that they can believe in their provider team and that the treatments are appropriate. The patient must feel that they can trust their provider before beginning with any therapy. The communication needs to be bi-directional and ongoing, and the family and patient should know that myths will be dispelled. Once it is built, if trust is broken, it can lead to a cascade of negative outcomes.

Visnegarwala from India shared a story that illustrated an ethical conundrum where two staff manipulated data, thus causing her to be involved in a 6-month institutional investigation related to her study participants. Her trust was broken, leading to hospitalization, PTSD, divorce, overdose, and eventually coma.

While trust is foundational to health care delivery, we know very little about it. Hurd and

colleagues (2017) have published on swift and traditional trust. Swift trust is easy to establish and happens in a flash during the early phase of a relationship. Traditional trust is built over time and takes longer to establish. In order to move ahead in the doctor-patient relationship, providers need to understand how important maintaining trustworthiness is and how it can be built, enhanced, and sustained. It is also suggested that when patients and families develop trust with a psychiatrist, counselor, or support group, the patient is more likely to stay, complete treatment, and take up the recommendation of the team.

One additional study found that trust was defined by "authentic, effective and transparent communication; mutually respectful and reciprocal relationships; sustainability; partnerships; and communication, credibility, and methodology to anticipate and resolve problems" (Dave et al., 2018). These initiatives contribute to enhanced partnerships that can be used to facilitate information gathering, a move towards wellness and appropriate treatments. The Roil story commented about the desire to be around others with mental health challenges because these people can exude positivity. They are, as he calls them, his honorable family. Others, such as Phoeun and Conroy, urged people to talk to someone you trust; they also said medical professionals should be more caring and empathic.

# People With Mental Health Challenges Need to Be Heard

This advice was mentioned multiple times. One author mentioned that parents should stop blaming their children, but, instead, should "listen attentively" to their kids, and that might avert their having to take medications. It was disappointing that many health care providers followed the letter of the law and could not think outside of the box. Some providers hear what someone says and think "medications," and others reject medications, leaving no choice but for their patient to go elsewhere (to multiple doctors) for treatment. One author wrote about screaming for help, but no one would pay attention. The Roil story mentioned friends over

family, because family often did not understand or accept what he was going through. A trusting relationship made all of the difference. Also, he spoke to the issue that sometimes all he needs is for someone to listen to him and not pressure him to do something. This is a common mistake families make—speaking for someone else, or speaking over someone else. And when people do speak up, like Ms. Oswald, we need to be respectful and listen to what they are saying and not unnecessarily sedate or physically force them. However, when it does happen, and the person is able to move on, they should be encouraged to speak out as a way to educate others as Ms. Oswald did going on the radio about her experiences to try to effect systemic changes.

The De Bry family wrote about doing their own work trying to find out about psychiatric illness specifically schizophrenia. They discussed the ethical conundrum of people being funded by the pharmaceutical industry, presenting biased results to patients, as well as undocumented conclusions of scientific studies. The "patient" at age 21 was no longer able to function as before due to medication side effects and described a long journey to find a "cure" on his own. This was unlike the uplifting story by Marchant; he was quite taken by a physician who actually admitted to himself and him (the patient) that he was wrong. He also communicated the wonderful feeling of people believing in him when he was allowed to speak up about his life and what he has been through. One progressive idea came from Canada, where the Mental Health Commission of Canada's National Psychological and Safety Standards aims to de-stigmatize mental illness by allowing people with lived experience to talk to others at work about their experiences, thus, providing educational opportunities about mental illness challenges.

## Love Is a Powerful Fixer

Multiple storytellers remarked on being grateful for love, for being shown love, and for friendship. Manthos advised parents to love unconditionally. They described friends as "making painful experiences more tolerable." One person suggested that

mental health professionals should be caring, and give people "a chance to feel accepted and loved."

When authors were discussing "love" you could imagine a smile on their face. In fact, Anonymous One said that their doctor "cleansed my soul through their love and patience." That is a powerful statement. Similarly, another author said that she was grateful for "unflinching support and love." One of the DeBry family golden rules included: the best medicine is unconditional love.

These stories remind me that, at this point in time, when a Warp Speed program was initiated to develop a vaccine for COVID-19 in the US and was done so within record time, perhaps it is also time for warp speed attention to mental health challenges. It would certainly make us all aware of the issues, perhaps reduce some stigma, and get people into treatment. If we can do it for COVID-19 with free vaccinations, why couldn't we do it for mental illness?

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# **Commentary**

# Experiencing Mental Illness: Suffering, Hope, and Healing

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**Abstract.** The experience of mental illness can be painful and isolating for those suffering in silence. Early symptoms frequently are confusing and disorienting for individuals and families, and stigma towards mental illness in societies across the globe contributes to further isolation from sources of support during the healing process. The evocative personal stories from a variety of cultures in this symposium provide a window into universal elements of the experience of mental illness, with the accompanying fear, shame, and stigma. The stories effectively illustrate the tension between personal autonomy and reliance on others, and the importance of trust in self and others in forming and maintaining a core identity. The stories also sensitively highlight the importance of resilience and persistence in the healing process, along with the essential role of social relationships and support from family, friends, and healers in building a stable identity and hope for the future.

Keywords. Mental Illness, Stigma, Social Support, Healing, Recovery, Personal Autonomy, Narratives

#### Introduction

The experience of mental illness is universal across cultures and includes the individual, the family, and the society at large. Although symptoms are experienced by the individual, inner experiences and suffering are communicated to others through behavior and language. What is communicated can engender empathy, thus drawing support and care, or can repel, reinforcing pain and isolation. How societies specifically deal with mental illness varies by tradition and culture, but all cultures throughout

history have had frameworks to enable individuals and social structures to classify and interpret emotions, perceptual experiences, and behavior. And, in the realm of nosology and contemporary science, culture and context interact with psychiatric diagnosis at multiple levels (Lewis-Fernandez and Aggarwal, 2013)

The personal narratives in this volume powerfully illustrate the universal complexity and emotional burden of mental illness, including the struggle of individuals to communicate their pain and suffering to others and engender empathy and support. A number of overlapping themes emerge from these personal accounts, regardless of age, gender, or culture. The most prominent themes include: Fear and confusion at the onset of symptoms; shame and self-criticism; the role of identity; stigma (from others and the self); and the centrality of trust in self and others as part of healing in a social context. Also nicely highlighted by the various voices in these personal accounts are a number of universal factors that are central to how mental illness is perceived in different cultures and how various paths to recovery are viewed. The authors highlight a variety of ways that recovery is defined: science vs. traditional healing and spirituality; autonomy vs. collaboration; social relationships and networks; characteristics of effective healers; resilience in the search for healing; and hope and altruism as core factors in successful recovery.

In this commentary, we will focus on the most frequent themes in these evocative accounts from an integrative psychiatry and social science perspective. We will then highlight how these first-person narratives can point the way to effective treatment and healing that incorporates individual talents and strengths, family and social networks, and professional expertise. The narratives, and various paths for treatment and recovery that they suggest, also naturally raise ethical issues that are impacted by cultural beliefs and value systems.

#### Fear, Confusion, and Shame

As with any illness, symptoms of mental illness may develop gradually and subtly so that the person may not even be aware of changes in emotions and behavior that are recognized by others. This is painful for the person and for their family and social support system. Three authors from widely different cultures and different psychiatric conditions described this particularly well.

Nataliya from Bulgaria felt social anxiety from an early age, "I was never good at making friends. All I could do is go out with my one friend and have a one-on-one conversation. Anything with more people perplexed me profoundly. In some ways, it still does, 17-odd years later. Actually, I don't remember much of my time at school, except that I feared every day like hell because it included random interactions with other students, teachers, people on the bus." As the years went by, the pressures of social interaction and work performance took their toll, contributing to profound depression that was experienced physiologically and emotionally, "I thought I was just very tired. However, things didn't get better with time. They transmuted into something else. I felt profound emptiness inside, an abyss of meaninglessness. I thought I would never feel normal again. Things that used to give me pleasure were mere burdens, something I should go through in order to make it to the end of the day and go to sleep. Sleep was my salvation. I was afraid to share all that with anybody because I was ashamed again, as with my social anxiety. I truly didn't know what was going on with me and that scared me out of my wits."

Bunna from Cambodia described social discomfort escalating to fear, then to confusion, paranoia, and delusions as her schizoaffective disorder developed, "I started to feel I was being watched by people everywhere I went. What happened was a sign or symptom of my illness that I did not know before. I thought of many things and my mind was full of confusion."

Syrena from Canada retrospectively describes the confusion of a manic episode on her wedding day that included jumping off a bridge into a river, "I wondered where all my family and friends were. Why weren't they here waiting for me? As this was my wedding day. I was so confused. Little did I know that at that moment, I was at the height of a severe mania and had been hallucinating, delusional, and in a state of profound psychosis."

# **Identity**

Identity is strongly influenced by culture. Western cultures emphasize an individual sense of self, whereas cultures that represent the majority of the world's population emphasize one's role and position in the family and society as the core of identity. This strongly correlates with the culture's

view of the importance of individual autonomy in making decisions, including when capacity is impaired by mental illness. This presents ethical dilemmas when judgment and insight are limited by psychotic symptoms, or the ability to adequately care for self, or even to protect oneself, is limited by severe depression.

Fehmida from India talks about her experience with bipolar disorder in the context of a severe blow to her professional identity, " Everything I knew to be true: my work, my marriage, my status in society, and my strength of mind, were all sucked into this black hole. I had a psychotic breakdown and required hospitalization. The trauma of work caused a complete melt-down of my ego as an accomplished physician and career woman." Her deep pain is experienced individually, but healing is strongly dependent on social bonds, "I am absolutely grateful for the unflinching support and love I have received from my family and close friends. I am extremely fortunate that I have five such people in my life who keep my substantiated and safe."

Glenn from Canada also refers to the delicate balance that often occurs between autonomy and dependence by encouraging others to "try to find friends who are not only friends but honorary family who are supportive, understanding, compassionate, and accepting", adding "sometimes all I needed was to have someone listen and not push me to do anything or offer advice unless I have asked."

Michael from the U.S. talks about the intense struggle between autonomy and social connectedness when struggling with his identity in the context of chronic suicidality, "My understanding of my own authenticity, my true self, literally who I am, sometimes feels ephemeral, ungrounded, nebulous. This is particularly the case as I emerge from a crisis period, wondering-with no small amount of fear—why is my brain trying to kill me? My identity is also social and relational. Who I am is partly defined by relationships to other people, especially to my friends and loved ones, and so the effect of my suicide on them must be included in my aesthetic musings on a good death. Since who I am is partly defined relationally, my death is also partly defined by the severing of those relations, and how death severs them can have tremendously different impacts on those left behind."

### Stigma

Central to identity is self-worth, which is often defined by one's internal sense of self that is influenced by social relationships and values. Across the globe, self-worth among those with mental illness can be severely impacted by negative sociocultural views of symptoms and behavior associated with mental illness. This ultimately results in stigma towards those with mental illness, who are marginalized from society. This marginalization, which often has roots in fear and ignorance, leads to further isolation of people with mental illness and reinforcement of symptoms that contribute to further shame, isolation, and marginalization, clearly described by Karin from the U.S., "This is the biggest stigma of all: the one I hold against myself. There is so much self-depreciation, so much beating myself up".

The social dynamics of stigma, including how stigmatization is reinforced through language and labeling (Corrigan, Markowitz & Watson, 2004), are perhaps the most frequently described experiences in these essays. The adverse impact of labeling on identity and integrity are vividly illustrated by Nataliya's hurt in being a "nutter," and Bunna's shame in being labeled as having "rok chet" or the more stigmatizing "sa sai brasaeat". Armando from Puerto Rico speaks for many of the other authors, "To those individuals who may be struggling with any mental health disorder, I would say that we are not just a diagnostic, a medication, or plain symptoms. We are humans and that should be our identity. With this, I mean to say that a diagnosis should not define what we are, or who we are".

## Trust in Self and Others

Another common theme in these essays was maintaining trust in self and others in the context of fear, confusion, fluid identity, and stigma associated with mental illness. Building and maintaining trust is

challenging during the onset of illness and during the years that follow, especially when there has been a history of trauma that has impaired trust in oneself and others. Building trust is particularly challenging at the onset of illness because the person frequently does not have a template for interpreting or classifying their confusing and frightening symptoms, the symptoms themselves impair trust, and because of shame that reinforces isolation from other people who could be supportive. Moreover, there is the human drive for integrity and autonomy that may further isolate and burden the person during a period of crisis. When reflecting upon hesitancy to involve others who potentially could be helpful at the onset of illness, Bunna recognizes that "I was not confident or brave enough to tell them about my situation".

Glenn could not rely on others who were in a position to help him, "My immediate family did not support me when I needed them the most. For example, when I was a teenager, I was told by family members that I would not be anything in this life. This made me feel valueless and destroyed my confidence that I could be successful in life".

Karin reflects, "Stigma has affected my life by allowing self-limiting beliefs to drive my self-worth and sabotage advancement."

#### **Implications for Treatment and Recovery**

These first-person accounts not only clearly describe the confusion and pain of mental illness and stigma, but they provide guideposts for successful treatment and recovery. An accurate diagnosis and comprehensive plan are essential for effective treatment, but the complexity of mental illness and its social determinants contribute to a frequently furtive process of recovery for many people.

It is very common across the globe for individuals and families, regardless of culture, education, or socioeconomic status, to sequentially or concurrently seek care from a variety of healers and sources. This sometimes leads to immediate success, but often it does not, reinforcing the suffering of the person and their loved ones (Backlar, 1994). The frequent tension among Western science, traditional forms of care, and spiritual and metaphysical healing approaches contributes to further confusion and frustration for individuals and families.

Bunna vividly describes her and her family's frustrating search for healing in Cambodia and Thailand. This search is replicated daily across both the developed and developing world, "Before receiving medical treatment from a psychiatrist, I was referred to see four different traditional healers. Some traditional healers I went to used a massage stick (chheu massaa), burned and sprayed the perfume, which was meant to get ghosts or evils away from my body. My mother and aunt were worried that I had issues with my brain, so they took me to see a doctor in Thailand to have my head scanned. The doctor said my head was fine".

Across the Pacific in a completely different culture, an anonymous Colombian author had a similar experience, "I tried to read self-help books from authors like Rhonda Byrne or Osho. According to them, to be happy, I only had to ask the universe and all my wishes would come true. I tried homeopathy, acupuncture, and other alternative medicines. I even consulted witches who read tarot or cigarettes (they read your future looking at the shape of the ashes as the cigarette burns) in hopes of hearing that someone was going to save me. Nothing worked. On the contrary, anything 'magical' was frustrating. If it was so easy, why couldn't I do it?".

The De Bry family from Belgium describe their search for healing for their son who was diagnosed with schizophrenia, "Because psychiatrists assume that schizophrenia is a genetic disease, stigmatization affected our whole family. To make matters worse, we were left with no hope, the psychiatrist added: '(1) it is incurable, which means disability for life; and (2) to survive, his use of psychiatric drugs, for *life, is required* . . . '".

In many of these essays, what comes through even more strongly than personal and family frustration and confusion about what represents effective healing is a belief in the importance of the social fabric. This social fabric is an interlocking network of family members, friends, traditional healers, clergy, doctors, and multidisciplinary treatment teams that are engaged to help care for the ill family member. Effective communication, acceptance, and care within the social network is seen by the authors as key to their recovery. We continually see this in our Intercultural Psychiatric Program that serves refugees and immigrants from dozens of cultures across five continents. (Boehnlein, Kinzie, Leung, Cary, Cheng & Sedighi, 2015). The De Bry family emphasizes the importance of "a team to accompany sufferers on their healing road".

Craig from Australia recounts a particularly impactful encounter with a hiking guide in Peru, "It was our guide Jimmy that helped me more than he may have realised. He said to me that he had seen bigger and heavier people complete the Inca Trail before and that he believed I could do this. I hadn't ever had anyone tell me, outside of the family, that they believed in me. Those words were like rocket fuel to me, and I continued onwards. The realisation that I could honestly do anything when I set my mind to it was the most important thing to come out from the Inca Trail".

Konstantinos from Greece notes the importance of caring and effective communication, "Friendship can make the painful experiences more tolerable, can reduce the fear that I may feel. Good communication and acceptance from the members of the community where I live improve my self-esteem. I enjoy being in contact with other people, socializing, talking about my interests, such as my love for pets and exercise. I am used to talking to other people about my experiences. This helps me to comprehend my own feelings and thoughts".

Armando highlights the importance of social connectedness in his recovery, "Self-isolation leads to more depression symptoms and sadness. However difficult and painful it might be, it is necessary to interact with others. Through an ongoing process of mindful awareness and introspection, support networks and therapy, I further assert my new self".

The anonymous Colombian author writes, "I have been able to heal because I allowed myself to bond".

The social network also includes the medical professionals that are called upon to assist. The professional's knowledge, training, and experience in providing ethical care are core to optimizing

treatment and recovery, and Frank (1974) emphasizes four essential qualities of healing and healers across time and culture that combat demoralization: an emotionally charged, confiding relationship with the healer; a designated place of healing; a rationale that explains health and illness and a path to healing; and, active belief and participation in the procedure or ritual process that restores health.

The Colombian author emphasizes the importance of these universal qualities of healers in describing a doctor that was central to the healing process, "Salvador was the first doctor who really connected with my suffering. I trusted him. I felt he reacted empathetically to my feelings and recognized that I was not exaggerating. He believed me".

Konstantinos emphasizes, "My advice to mental health professionals is to be caring and give the people who suffer from mental health problems a chance to feel accepted and loved. They need to avoid any prejudice and stigma in their contact with people with mental health problems". Additionally, another pervasive theme in successful healing and recovery highlighted by several authors is the importance of altruism and active engagement in assisting others with their recovery, again emphasizing the universal importance of building and sustaining effective social networks. This sometimes can occur through group treatment, or it can occur through engagement in mental health advocacy.

Glenn explains, "I speak on my own incredible story to inspire others so that they can have similar positive outcomes in their lives. What has worked well for me is being around other people with similar mental health challenges or issues and staying busy with kind and compassionate people in my work life, volunteer life, and community".

Karin reflects, I connect deeply with my family and friends and feel like an indispensable contributing member of society".

## Conclusion

Viewing healing through a social lens does not obscure the individual person who is struggling, often silently, as described by many of the authors and by William Styron in his classic memoir of

depression (1990), "For those who have dwelt in depression's dark wood, and known its inexplicable agony, their return from the abyss is not unlike the ascent of the poet, trudging upward and upward out of hell's black depths and at last emerging into what he saw as 'the shining world'. There, whoever has been restored to health has almost always been restored to the capacity of serenity and joy, and this may be indemnity enough for having endured the despair beyond despair".

There is a dynamic interplay of individual, sensory, and psychological experience with the social environment within which the individual suffers, but also eventually heals. The effective balance between autonomy and agency and accepting support and care from others is often central to sustained healing and recovery. Nataliya emphatically states, "Despite all the struggles I've been through, I'm grateful for love. That makes me want to keep going. I've learned to be more tolerant, more patient, more compassionate, and thoughtful". Emphasizing agency and hope, she effectively ends her evocative story by quoting Andrew Solomon (2015), "Every day I choose, sometimes gamely and sometimes against the moment's reason, to be alive. Is that not a rare joy?".

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