

Discourses of Madness and Me: Critical Examinations of Western Discourses of
Madness and Psychiatry

Debut
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Abstract

This paper is a critical examination of western medical paradigms alongside histories of psychiatry that argues for a culturally situated approach to mental health advocacy that maintains the importance of the physiological foundations of traditional biomedical approaches to disease. In doing so, I examine the discourses of madness, and society's attempts to control and "fix" what is deemed "mad" through a historical lens. My position and critique utilizes a reflexive narrative process embracing my identities both as a consumer of mental health services and as an advocate for those with mental illnesses.

Statement of Professional Responsibility

In submitting the attached paper or proposal, I recognize that this submission is considered a professional responsibility. I agree to present this panel or paper if it is accepted and programmed. I further recognize that all who attend and present at ECA's annual meeting must register and pay required fees.

Here we go another doctor, another drug, and another diagnosis.

“Erin, can you describe to me the symptoms you experience that lead to your bipolar diagnosis? *My symptoms? He must mean my life. My life is a chaotic mess; a tornado that destroys everything in its path, a waste of time, of resources, and hope.* Dr. Ayers¹ is my last shot, after this my parents, my friends... well, after this we’re all giving up.

“I’ve been manic twice, but mostly I am on the depressive side of the spectrum.” This answer solicits the sympathetic doctor nod designed to signal to me he is listening. I hate that nod. It feels condescending and patronizing.

“You said earlier you have a history of eating disorders. Do you still participate in bulimic behaviors or have the compulsion to?” My insides twinge.

I hate this question.

“Yes, and I hate it. I feel so weak, and I try so hard...” I quietly plead, feeling as though I’m asking for his forgiveness. There are no words to convey my powerlessness to him. Expecting the usual, slap on the wrist response. His answer surprised and comforted me.

“I’m not surprised you are struggling so much Erin. There have been studies that show that bipolar disorder significantly affects the part of your brain that guides impulse control. If you cannot keep your medicine down to help your bipolar disorder, your bulimia will be harder to manage in return, which then makes it difficult to keep your medicine in your body to treat your bipolar...” As Dr. Ayers finished explaining to me why my brain sucks so much, I sat in a daze in my chair. Sadly, this is so familiar, having strangers poke and prod into my inner most parts, attempting to make sense of my chaos. *I just want to go home.*

“How do you feel about working with me Erin?” Dr. Ayres asked.

¹ Dr. Ayers is a pseudonym

Taken aback by the question. I said, "Good I guess." Still just waiting for the appointment to be over.

"Do you ever believe you will be able to live a full and productive life?"

My eyes filled with tears, and I choked back the words: "I don't see how that is possible." I sat back in my chair defeated. I left school. I can't work. I can't get out of bed most days. My parents are preparing for me to live with them forever.

What a stupid question he is asking me.

He didn't wait for me to answer the question and followed with: "I became blind at eight years old, and it is only through the loss of my sight that I have been able to truly see the world." Stunned, I didn't know what to say. So I remained silent. He eventually broke the silence with a plan to move forward.

"I'm going to order some tests. I need a lithium level on you, your thyroid checked, and I want to get your liver and kidney functions tested.... We're going to start weaning you off of some unneeded medication. I want to see you back here in one week, and then I'd like to get you and your family in here the week after that..."

Dr. Ayres stood up, and I followed. He stretched out his hand and said: "It was wonderful to meet you Erin, and I look forward to working with you."

I put my hand in his, "Thanks, Dr. Ayres."

I left that evening, two hours later. In one hand, I grasped a list of medical tests, and a list of drugs to begin the weaning process. In the other hand was a document detailing my upcoming appointments. And in my brain Dr. Ayres's self-disclosure,

Why did he tell me about losing his sight? Does he think I can live a full life? How can he appreciate his blindness?

I start this paper with a story describing my first interaction with Dr. Ayres as an exemplar embracing both a social approach to psychiatry, while still emphasizing the importance of physiology. Sitting in the office with a new doctor, Dr. Ayres, I embodied a whole person, sick and well, a person with a past, a present, and future. Dr. Ayres recognized my cultural and social situatedness through our conversation about my beliefs regarding the possibility of living a full life, and in his sharing of himself with me and his disability became a partner rather than dictator of care. Dr. Ayres used traditional biomedical language describing my illness as symptoms, labs, and physiology. Helping to convey to me that my illnesses are not my fault, and my inability to control them does not reflect a flaw in character, willpower or strength, but more so a problem outside the realms of my control. The tension between the matter of the physical mind and the spiritual and social selves of being are evident in the historical discourses of ‘madness’ and the formations and tensions of medical paradigms throughout history. This paper examines those tensions and shifts through the discourse of ‘madness’ in western culture.

It is arguable that psychiatry is the most controversial field of medicine (Shorter, 1998). Historically its legitimacy has been questioned through the lenses of religious ideologies and beliefs, legal and ethical concerns and considerations, and the very scientific paradigm in which it resides (Shorter, 1998). There seems to be nothing more mysterious about the human body than the brain. The treatment of the mentally ill, and throughout time the perennial question: “what do we do with them,” reflects that. Often choosing a position in the larger societal conversation regarding the legitimacy of psychiatry, mental illness and appropriate treatment models is a simple one. It’s less simple for those of us who are reliant on this controversial and stigmatized field of medicine that is constantly being questioned as legitimate (Nguyen-Finn, 2012).

Critical examinations of medical paradigms alongside histories of psychiatry underscore the need for a culturally situated approach to mental health advocacy that maintains the importance of the physiological foundations of traditional biomedical approaches to disease. To do this, I examine discourses of madness and psychiatry through the lens of Western medical paradigms. First, I engage the pre-modern and pre-medical conceptions and portrayals of ‘madness’ and morality. Second, we move through the age of reason and enlightenment, focusing on the reflection of modernist thinking and the biomedical paradigm’s influence on psychiatry. Third, we examine the movement towards post-modernity and social models of health. The final section underscores the need for embracing aspects of both models in advocacy efforts. As I write this paper, I embrace my identities as both a consumer of mental health services and an advocate for those with mental illnesses. In doing so, I utilize a reflexive narrative process.

Spirit Madness and Morality

Before the age of reason and the scientific reign over the body and mind, ‘madness’ was intricately linked with forbidden knowledge, spiritual revelation, truth, and philosophical expression (Foucault, 1988). To the church, madness was a moral issue. The church viewed the ‘mad’ as being punished for sin or being tested in hardship. Christian and Jewish influences in Western culture render the Bible’s illustrations and discourses of ‘madness’ influential. In early Christianity healing the mind, body and soul of an individual occurred through religious practices (Idler & George, 1998). Evidence of this, the Bible records Jesus’ miraculous works of healing illnesses through faith (Favazza, 1982). Today, while it is common for churches and Christian denominations to have renounced their belief in the demonic origins of mental illness, replacing it with natural and psychological explanations, there is still widespread belief among

Christians that mental illness is caused by separation from God and demonic possession (Dain, 1992; Favazza, 1982)

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It was well past 9pm and the interfaith chapel was empty other than Samantha² and myself. She dragged me there after small group. At first we sat silently, staring at each other. I had nothing to say, nothing that could make her feel better about my life anyway.

“I’m worried about you.” Samantha whispered. Tears begin to stream down my face, like a waterfall.

“I can’t stop.” I wailed louder than I intended.

“I believe in you,” she stroked my arm while pulling out her Bible. Samantha was my small group leader; she was the mothering type and lived out her belief that everyone can be saved with love. I was her current project. But I knew it wouldn’t last long.

Samantha continued, “. . . more importantly, God knows your pain and your struggles. I can prove it to you.” She opened her Bible, shuffling through the pages and read out loud:

We know that the law is spiritual; but I am unspiritual, sold as a slave to sin. I do not understand what I do. For what I want to do I do not do, but what I hate I do. And if I do what I do not want to do, I agree that the law is good. As it is, it is no longer I myself who do it, but it is sin living in me. For I know that good itself does not dwell in me, that is, in my sinful nature. For I have the desire to do what is good, but I cannot carry it out. For I do not do the good I want to do, but the evil I do not want to do—this I keep on doing. Now if I do what I do not want to do, it is no longer I who do it, but it is sin living in me that does it. So I find this law at work: Although I want to do good, evil is right there with me. For in my inner being I delight in God’s law; but I see another law at work in me, waging war against the law of my mind and making me a prisoner of the law of sin at work within me. What a wretched man I am! Who will rescue me from this body that is subject to death? Thanks be to God, who delivers me through Jesus Christ our Lord! So then, I myself in my mind am a slave to God’s law, but in my sinful nature a slave to the law of sin. (Romans 7:14-25, English Standard Version)

“So, is my bulimia sin?” I questioned, terrified of the answer.

² Samantha is a pseudonym

“It is the result of sin because we live in the human condition of sin. That’s why we need Jesus.” Samantha responded. Standing up I walked over to one of the long narrow windows lining the room. I didn’t want to believe in God anymore but I didn’t know how to stop. I pictured myself as a little girl kneeling in Mass asking God to forgive each of my sins. I held this mental image of each sin equating to a little black “x” on heart believing that once my heart filled up I was doomed to Hell.

So how do I get rid of it then? How do I get better? Is it my fault?

Body Madness

Entering the age of enlightenment and modernist thinking the biomedical paradigm of medicine emerges as the dominant framework for understanding and approaching human physiology. This shift in thinking shifted the discourse of madness away from the spiritual and philosophical realm towards the physiology of the brain (Alonso, 2004). According to Decon (2013) “The biomedical model posits that mental disorders are brain diseases and emphasizes pharmacological treatment to target presumed biological abnormalities” (p. 846). The focus on the physical body demonstrates a stark contrast to the pre-modern discourse of spiritual revelation and philosophical expression. This shift in the social discourse from ‘madness’ as spiritual to ‘madness’ as biological gave society a newfound perceived control over ‘madness’ or mental illness and the uncertainty and fear that accompanied it (Foucault, 1988).

As the mentally ill were warehoused, categorized, ‘treated’ and medicated individuals in mainstream society were able to distance themselves both mentally and physically from ‘madness’ (Nguyen-Finn, 2012). Illness and disease as a possibility became treatable, henceforth controllable. Sedwick's (2013) asserts the traditional scientific paradigm "craves the comfort and security that the vision of a life devoid of suffering promises" (p. 317). This

highlights and emphasizes the medicalization of mental suffering that we see during this time. This idea is congruent with the notion that the biomedical model seeks to "fix" rather than understand and explore illness, and suffering as part of the human condition (Sedgwick, 2013).

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I stared at the little white paper cup filled with colorful pills trying to pretend they were candy.

“Just swallow them.” Someone said from the line behind me clearly annoyed. I could hear the med nurse Jessica smacking her chewing gum, loudly as ever staring intently at me.

I don't want these.

“Come on, we don't have all day.” Another patient behind me grumbled.

I don't want these.

Jessica³ smiled sweetly “Erin, if you take all of your meds without a problem you will be discharged much more quickly. I know you want to get on with you life.” I tossed the pills into the back of my throat in one quick motion, and down them with a gulp of water. There isn't much of a life for me to ‘get on with’ but I did want to get out of the locked ward as soon as possible. I hate hospital air. A dull cheer erupted from the line behind me as I opened my mouth wide for Jessica to examine the insides of my cheeks. Walking away I watched the next person step up to the window to receive morning pills.

It doesn't matter what we want.

The reframing of the discourse of ‘madness’ to biology and physiology removed some of the blame, shame and guilt that developed during pre-modernity (Alonso, 2004; Schreiber & Hartrick, 2002). A number of scientific and medical advances that arguably have been pivotal

³ Jessica is a pseudonym

not only for the development of psychiatry as a field but also for understanding the development of the human body (Alexander, & Selesnick, 1966). However, these advances came with the dehumanization of patients by doctors. This dehumanization led society to warehouse, shackle, tie down and lock up the insane with the poor, the criminal and the deviant (Nguyen-Finn, 2012). This coupled with the biomedical paradigm's framing of the patient as recipient creates disempowering situations for the patient.

Within the traditional biomedical model, the ill and the disabled are the recipients of other people's expertise, not contributors to healing (Richards, 2008). This assignment of roles creates a gap in understanding and prevents gaining access to more contextual understandings of these stigmatized illness experiences. The 'doctor as expert' and 'patient as receiver' system disempowered an entire population, in this case, the mentally ill and facilitated an environment of cultural dependency. An entire population was institutionally silenced; for we hear and have the dominant medical professional's narrative regarded as culturally more legitimate as well as more prevalent than those who "receive" treatment. This bias towards the providers voice is in accordance with the biomedical perspective; not the patient or illness bearer. These professional lenses are intrinsically biased from the position as part of the dominant meta-narrative (Richards, 2008). Moreover, knowing the physical aspects that accompany illness does not necessarily mean a person recognizes the social implications of illness (Richards, 2008).

However, history shows society can only silence a population for so long. The horrendous physical environment and treatment within the insane asylums and mental hospitals of the 18th century were gradually addressed (Nguyen-Finn, 2012). Major players included Phillipe Pinel in the 1700s, and his development of 'moral treatment' based on humane psychosocial care and moral discipline (Shorter, 1998). In 1812, Benjamin Rush, advocated

against restraint, coercion, and physical punishment, believing in a more ‘normal’ hospital experience for the mentally ill compared to previous extreme warehousing conditions (Shorter, 1998).

More recently former patients, also known as ex-patients, have used their experiences within asylums to draw attention to the ‘oppressive’ conditions within psychiatric institutions within the United States (Alexander, & Selesnick, 1966). Three seminal books came out in the 1950s that made waves regarding the treatment of patients in psychiatric care: Thomas Szasz’s *The Myth of Mental Illness*, Ken Kesey’s *One Flew Over the Cuckoo’s Nest* and Erving Goffman’s *Asylums*. During the same time, David Rosenhan an American psychologist also began publically challenging the validity of psychiatric diagnoses (Alexander, & Selesnick, 1966; Mechanic & Rochefort, 1990).

These shifts in thinking about the ethics of treatment of the ‘mad’ or mentally ill and the emerging questions regarding biology and physiology underscored the areas of tension between the biomedical model and its application to psychiatry as a field. These tensions, apparent problems and gaps in the traditional scientific paradigm of the biomedical model influenced scholars to reorient the focus of health to center on experiences, perspectives, culture and identities (Goldenberg, 2010).

Adolf Meyer was one of the most prominent psychiatrists in the 20th century, emphasizing the need for collecting detailed case histories on patients (Lidz, 1966). He stressed the importance of the biological, psychological, and social factors relevant to each patient’s life (Lidz, 1966). He was influenced heavily by both Freud’s psychoanalysis and Kraepelin’s shift from symptomology to a system of clinical classification. As Freud’s psychoanalysis was adopted more heavily into psychiatry, the field changed completely (Lidz, 1966).

The inclusion and embracement of Freud's psychoanalysis are what brought psychiatry into mainstream medicine (Strand, 2011, Wilson, 1993). The field moved from being tasked with simply managing the 'mad' or 'insane' to treating individuals as people with mental illnesses. This marks a shift from treating diseases to treating people (Wilson, 1993). Through much of the 1950s, the field itself remained divided, however, with one group being the "analytic-psychological" oriented providers and the other group focusing on the "biological tools" (Strand, 2011). As the field psychiatry legitimized and grew more than ever before, so did the voices opposing it.

In the 1960s the anti-psychiatry movement developed. The movement led by former psychiatric patients, also known as ex-patients, as well as other intellectuals and advocates (Dain, 1989). They advocated for not only better treatment for those deemed mentally ill, but also questioned the existence of mental illness as a disease (Shen, 1999; Dain, 1989). Rather than a disease an individual possesses, the group posited that the problem lies within how society treats and accommodates different types of human beings. The Anti-Psychiatry Movement in particular was very critical of the biological and physiological measures taken to treat individuals labeled or categorized as having mental illnesses (Van Praag, 1978). One of the effects of the movement was the reframing of 'the problem' from the individual who is mad; to society who cannot accommodate to different groups of people. The Anti-Psychiatry reframing of the discourse of 'madness' resembles Malley-Keighran and Mary Coleman's (2014) description of the social model of disability. Additionally for faith based communities, this movement reiterated a historical religious discourse that 'madness' was in fact a spiritual problem and encouraging individuals to seek counsel with religious leaders instead of mental health professionals (Stanford, 2007).

This model sees disability as a socially created problem, rather than an individual problem or attribute of a person. This model insights a political effect that the actual problem is created by an "unaccommodating environment" created by attitudes and features of the greater social, cultural and political context. In terms of guiding principles, the social model views disability through a lens of 'oppression,' construing it in terms of society's failure to meet the needs of all of its members (Malley-Keighran & Coleman, 2014; Hughes & Paterson 1997). This social model is indicative of a more holistic approach, as it acknowledges health not merely as a static state of being, but more points towards a continuum of positive well-being (Hughes & Paterson, 1997; Malley-Keighran & Coleman, 2014). The biomedical model falls short in defining health as a holistic dimension, as it addresses health exclusively in terms of a single condition: the absence of disease.

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"Hi, Erin" I could hear the pain in my mother's voice as I pressed the phone to my ear. The phone only rang once; my mom has been waiting for my call for days. I had finally been granted phone privileges.

"Hi, mom." I exhale, fighting back tears. I fight everything inside of me that is telling me to beg her to book me a flight home. I want to promise her I'll be better and I'll take care of myself and that I'll never ever need help ever again. I want to apologize for being so difficult and causing so much pain. I want to tell her I can do this. But I don't. Shaun⁴ the behavioral tech sits next to me writing notes listening to our conversation. I hear my dad yelling in the background.

"How are you? Are you okay? Do you need me to send you anything?" Mom asked, trying to comfort me from across the country.

⁴ Shaun is a pseudonym

“No. I’m okay. Who is Dad yelling at?”

“He’s on the phone with the insurance company. You know, the usual.” My chest tightens, and my skin burns hot. I am hurting them. Treatment is thousands of dollars a day, money that we don’t have. I think about my dad’s heart, and his blood pressure. This is going to kill him. I’m going to kill him. I hear more yelling.

“What’s going on? Are they denying coverage? I’ll come home.” I cannot cost my family everything. I’m not worth it. This might not even work. I cannot ruin their lives.

“It’s just something about a form sweetie; we’ll get it straightened out.” My heart sank. I could hear the lie in her voice. Tears began to burn. She can’t hear me cry.

“I love you mom but I have to go, someone else needs to use the phone.” I force the end of the conversation about to burst into tears.

“I love you too Erin, get better.”

“I will mom.” I hang up the phone and rest my forehead on the wooden table where Shaun and I sat. Then standing up I pushed the phone onto the floor screaming “I CAN’T DO THIS.” Tears flow, unstoppable, my head spins and my skin tingles. Shaun moves towards me.

“DON’T FUCKING TOUCH ME.” I screamed storming past her and into the hallway. I wanted to rip all the skin off my body, so I pace the front hallway up and back up and back, crying loudly. Marie⁵, another behavioral tech ushered the other patients into the common room and Shaun sat in the hallway with me as I slid my back down the wall sobbing, grasping at my skin tightly pulling for relief.

“Susan⁶ is on her way in Erin.” Shaun said softly.

“I don’t need a fucking therapy session. I need a plane ticket.”

⁵ Marie is a pseudonym

⁶ Susan is a pseudonym

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The response to the change in cultural discourse and sentiment regarding the ambiguity, mistrust and critique of psychiatry is evident on many levels. Politically there was a mass deinstitutionalization from the large-scale mental hospitals and asylums. John F. Kennedy introduced legislation that placed the responsibility for treating individuals with the community mental health centers. In this paradigm individuals with mental illness would be able to seek voluntarily treatment if needed (Mechanic & Rochefort, 1990). This mass deinstitutionalization not only released individuals from insane asylums, it also increased access to psychiatry to a larger population base. This marked a shift from a smaller more concentrated populations being treated for severe mental illness to a much broader and wider scale of individuals asking for help both with pharmacology or some form of psychoanalysis with a wider range of issues with varying levels of severity (Mechanic & Rochefort, 1990; Wilson, 1993; Grob, 1995). This shift accompanied much criticism within the medical community and culturally.

Insurance companies began rejecting coverage of mental health services because of both the expense and the ambiguity of success that does not fit into the dominant western biomedical paradigm of certainty and cures (Wilson, 1993; Grob, 1995). Together the criticism of the biological and physiological aspects of psychiatry that occurred within the anti-psychiatry movement in combination with the cultural rejection of psychoanalysis ultimately led to diagnostic psychiatry (Wilson, 1993; Mayes & Horwitz, 2005). Diagnostic psychiatry focuses primarily on the description of and categorization of mental illnesses, rather than their cause; this is the discourse and model found in the DSM-III and beyond (Wilson, 1993; Mayes & Horwitz, 2005). This clinical categorization of people is intended for treatment and practical purposes, but it is criticized for squashing human experiences into categories (Kirk & Kutchins, 1992).

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Leslie⁷ knows this game. We sit in her office and stare into each other's eyes. I will not break. I will not speak first. She called my parents, which is complete bullshit. Claiming she was worried about me because I didn't show up for an appointment. I have no privacy, no rights, and no autonomy. Everything I do is under a microscope all the time and everyone is constantly analyzing my behavior. I can't breathe, think or sleep without someone getting concerned noticing symptoms, behaviors, patterns or problems. I am a lab rat.

"Erin do you trust me?" Leslie asked.

"No." I stared at the floor, determined to run this conversation into the ground.

"Why not?" Leslie tried again.

"I don't trust anyone."

"Why don't you trust anyone?"

"Because I just keep getting hurt." I said adding aggression to my tone, letting her know this conversation was not about to happen. She surrendered, Leslie has been my therapist long enough to know when I've shut down.

"Erin, I'm recommending that you begin dialectical behavioral therapy. It was developed for the treatment of borderline personality disorder."

I look up. "You think I have borderline personality disorder?" *Panic. This means I'm bat-shit crazy.*

"Let's look at the criteria. In order to meet the diagnosis, you have to meet five out of the nine criteria." She pulls out a book and begins reading a list to me. I didn't listen. *Maybe I am borderline, maybe I am unfixable, maybe I am bat-shit crazy.*

⁷ Leslie is a pseudonym

[One week later]

“How have you been doing Erin?” Dr. Ayres asked

“I’ve been okay. I’m starting DBT next week.” I explained.

“That’s great. I think DBT is helpful for people with bipolar disorder.”

“Actually, Leslie thinks I have borderline personality disorder,” I said quietly, as my face burned hot with embarrassment.

“Really?” He sounded surprised. “I am going to have to disagree with that. I’ve worked with many individuals borderline personality disorder, and while you have some very significant social implications as well and traumatic experiences that influence your behavior I would not diagnose you with BDP.”

“Oh.” I said, confused.

“Erin, this isn’t an exact science, and what is less important is how your doctors describe your symptoms and, what is more important is how effective the interventions are.” Dr. Ayres stated simply.

If they don’t know what is wrong with me, how can they help me? How will they know what interventions to use? If this isn’t an exact science why am I taking fist fulls of pills every day? What am I even doing here? Are these all just guesses?

In that time and space with Leslie as I categorized myself as a borderline based on the DSM-IV, I felt silenced and my experience was squashed to fit the narrative within the dominant model of diagnostic psychiatry. It had huge implications about my identity. With the label, I also embodied the stigmas and shame that the label borderline carried. I then became incredibly confused when my therapist and my psychiatrist disagreed about this diagnosis. Confusion, fear, and discomfort welled up within me as I realized that there isn’t an exact answer as to what is

‘wrong’ with me. There isn’t a definitive, absolute problem and solution. But while this science may not be ‘exact’ and the label might vary depending on whom I talk to the realities of my suffering and pain remained. Those things were and are very real. Dr. Ayres’ emphasis on the importance of the effectiveness of the intervention had an impact on me. This emphasis on interventions that work for me changed the script from labeling and categorizing me to empowering me to start narrating my experience of illness and recovery in terms of what works and doesn’t work for me.

When we acknowledge that individuals are socially constructed and ‘messy,’ non-rational, and often non-linear and situated within culture and context we realize that the biomedical model no longer fits the treatment of what was once labeled ‘madness’ and now called ‘mental illness’ (Bucholtz & Hall, 2005). Moving from the traditional biomedical approach of psychiatry and to a more social and culturally contextualized paradigm recognizes that illness and disability do not happen in a vacuum (Cardillo, 2010). Even in our history of socially isolating the ‘mad’ with the poor and the deviant, isolation was never truly successful. There were enormous economic effects, and ripples of social, and political retaliation over time (Mayes & Horwitz, 2005). Our past, our present, and our future, our environments, our relationships and our cultures all affect us as ill or disabled just as being ill and disabled affects the context of the rest of our lives (Frank, 2013, Cardillo, 2010). And in the realm of medicine, psychiatry or otherwise, this context cannot be removed, even when attempted.

Alternately a socially and culturally contextualized paradigm for thinking about disability and illness is the social model of disability. This framework shifts the ‘problem’ from the individual to society citing the lack of accommodation as oppression. This line of thinking is similar to the underpinnings of the anti-psychiatry movement in the 1960s and 1970s referred to

earlier (Shen, 1999). This model offers the important social and cultural context that the biomedical model doesn't engage (Malley-Keighran & Coleman, 2014; Hughes & Paterson 1997). We know that humans are relational communicative beings, and our identity is continually re-negotiated through the communication and interaction (Frank, 1995; Bucholtz & Hall, 2005). As illness bearers, this identity re-negotiation through communication and interaction is vital not only to how society conceptualizes 'illness' but for how individuals perform their illness identities.

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"Erin, I hate myself. I'm such a failure. I'm never going to be able to recover."

Bethany^{8,9} whispered in a sheer panic. She was at the airport, again.

"You are not a failure. I love you so much, and I think you are incredibly strong." I said, knowing that in this moment no words could possibly help ease the fear and self-hatred I knew she was feeling right now; that I have felt myself.

"This is my ninth time going into inpatient treatment; it's so embarrassing, why can't I just get a grip? My parents are so mad at me." As Bethany spoke I listened and remembered the day I almost didn't get on my connecting flight to Arizona for treatment, frantically calling my friend Rachael from the Atlanta airport.

"Bethany, listen to me, they are sad and frustrated with your eating disorder, not you. They want you to get better. Yes, they are sad and scared. But it's not your fault. You are not choosing this. Sometimes people think it's a choice because it looks like one, but no one chooses torture, no one chooses hell." As I tell Bethany much of what Rachael told me that day I silently

⁸ Bethany is a pseudonym

⁹ Bethany's past and personal characteristics are fictionalized

pray that she gets on the plane. Thinking about how different my life would look now if I never got on my connecting flight.

“I hate this.” Bethany whispered. “I hate being alive. It’s so hard to describe to people how sick eating makes me feel. Food is painful for me to put in my stomach, and it does not even taste good. I wish I wanted it. I wish my body wanted it. I wish I liked how it tasted.”

“I wish that for you too...” I responded remembering the day Bethany and I got in trouble for spraying furniture polish all over House C’s wooden floors and inviting everyone over to slip n’ slide in our socks. It was Megan’s birthday and we wanted her to have fun even though we were in treatment. We all had to drink supplements for burning extra calories, but it was totally worth it. I smiled to myself remembering how alive we all felt that day.

“I would change it if I could. I am so over this, people assume that I like being sick – I just want to die, it would be so much easier.” My heart broke hearing her wish her life away.

“People are ignorant when it comes to mental illness, especially eating disorders. You know that. No one understands that this illness is mental, physical, spiritual... everything. Don’t let their ignorance keep you sick though. This is not your fault. You need this treatment. You deserve this treatment. You can get better.” I can feel myself getting angry. Bethany developed anorexia when she was sixteen after surviving a car accident that killed her older sister. The night Bethany told me her story she said that in one day she lost her sister, her appetite and her will to live. She believes she caused that accident somehow and most of her waking hours are spent trying to piece together the events. Ever since then she has cycled in and out of treatment facilities, entering each time with her weight, heart rate and body temperature having dropped to alarming numbers and getting discharged after her insurance company has decided she is physically stable refusing to authorize anymore days.

“Erin, my plane is boarding.”

“I love you - I’ll write. You can do this.” I said softly trying to send love through the phone.

“Promise?”

“Of course.”

One of the biggest challenges for people with mental illness, myself included, is wondering if we’re actually sick with some disease or if we’re just stupid and difficult. We’re sent conflicting messages from everywhere: different doctors, family members, friends, church, and school just to name a few, and just as there are seemingly endless opinions and possibilities floating around we are constantly having to decide what we believe is happening within us while making life and death decisions based on those beliefs.

The emphasis on the social and cultural context and the oppression that a person faces because of the historical meaning and status associated with being mentally ill or disabled is incredibly important. However, without also acknowledging the physiology of the body and the brain that are also relevant as embodied illness bearers everyone in society suffers, but primarily those who are mentally ill. Nadine Nehls (2000) states, speaking about recovery from borderline personality disorder, “[recovery]...it is both elusive and fundamental. Nonetheless, traditional and alternative approaches to understanding improving should be pursued.” (pg 68) Here Nehls captures the complexities associated with ‘madness’ and mental illness starting with pre-modern medicine and relates back to what Dr. Ayers impressed on me in my discussion with him about conflicting diagnosis and that the power is not within the description of the symptoms or the ‘problem’ but the effectiveness of the solutions and interventions for the sufferer.

Stephen Brookfield (2011) in writing about his experiences with depression highlighted the importance of embracing the biomedical narrative in order to come to a point of acceptance and understanding of his illness. Brookfield's reframing back toward the biomedical narrative helped him manage the debilitating effects of shame that accompanied his mental illness and enabled him to manage his illness more effectively. For Brookfield that involved rejecting the destructive ideology surrounding illness, weakness, and mental health. That he learned was much more deeply and culturally embedded within him and accepting a narrative based on the idea that depression had physiological origins (Stephen Brookfield, 2011).

Understating the role of the physiological aspect of the modern biomedical narrative as a discourse to reduce shame, guilt and fault in the larger cultural and social conversation about mental illness is essential. However, as seen throughout tracing the historical development of psychiatry without also maintaining an understanding of the social and cultural context of each patient effective treatment is not possible for patients. And even more so the field becomes culturally scrutinized in ways that make it challenging for individuals seek help.

Madness Narrative & Advocacy

One current method for addressing the patient more holistically physiologically, culturally, and socially is a movement towards narrative medicine. Rita Charon (2006) defines Narrative medicine as: "medicine practiced with these skills of recognizing, absorbing, interpreting, and being moved by the stories of illness" (p 4). Charon describes how honoring patient narratives in the practice of medicine create 'bridges' between the doctor and the patient where there usually divides in feelings, beliefs, understanding and experiences creating a more mutual partnership between the patient and the provider. Charon, like many others recognize the significance and position of the ill person's perspective. She states: "The powerful narrative of

illness that have recently been published by patients reveal how illness comes to one's body, one's loved ones, and one's self" (p. 65). Many doctors, like Charon advocate for narrative, literature and writing to be required courses in medical school. So for doctors using narrative as a medical tool shows great potential in creating positive, productive and effective provider-patient relationships. However, it is important to recognize that in order for narrative medicine to occur the patient must be able to narrate their experience. Unfortunately when dealing with patients in need of psychiatric care you're encountering a population who as symptoms of their disease may struggle to or be unable to tell or describe to a doctor or anyone else what they are experiencing.

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Katherine¹⁰ sat across from me with her arms folded in her lap. She has short, fat arms that don't look like they cross comfortably.

I hope my arms never look like that.

I cross and re-cross my own arms a couple of times, to see how they feel and promise myself to start measuring them again every morning. Her office is what my mom would call a 'homemade hurricane.' There are stacks and piles of papers covering her desk. Little cards and notes from colleagues and clients scattering the windowsill. Her bookshelf filled with titles such *Breaking Free from Compulsive Overeating, Childhood Trauma, and What to do if Your Child has an Eating Disorder?* Coffee cups, chocolates, individual packs of pretzels and crackers littered various tabletops and file cabinets. I was appalled. No professional anything should be this disheveled. I promise myself I will clean my dorm room when I got back.

"How was this week?" Katherine asked.

"Fine." I didn't know what to say. Katherine is an okay therapist from what I can tell. She

¹⁰ Katherine is a pseudonym

seems genuine. I just don't know what I am supposed to do. I don't know what she wants from me.

"Well, that's good... makes my job easy." Smiling, she follows with a deliberate lightness in her voice. I rolled my eyes; we've had this same exchange every week for the last six weeks now.

"What kinds of things have you been doing this week?" She asked further.

"You know, classes and stuff... the usual." I lie. I hadn't been to class all week. I've barely gotten out of my bed. To make things worse my roommate keeps asking what was wrong. But I doubt Katherine cares or wants to hear about the stupid drama with my roommate.

"Hmmm, good." Katherine nods tilting her head to the side with less lightness in her voice. She knows I'm lying. I know I'm lying. I'm not even trying to be good at it. It's too exhausting.

"Erin, what do you want to get out of therapy?" Katherine asks.

"To get better." I hate when therapists ask this. It's like saying: *Hello moron, you're failing at therapy, so figure it out and stop wasting my time.*

"And what does 'better' mean to you?" She continues to prod.

"Healthier I guess. I need to stop binging and purging. I'd like to be less depressed. I want to like life again." The answers are easy. She should know them by now. The fact that she is asking is slightly concerning. Why have we been meeting for almost two months now if she hasn't been listening?

Dear God,

Why are these my thoughts? Why do I want to hurt myself? Why is this happening? I am not strong enough. I do not know how to be honest about these things. I want to scream I'm

humiliated, powerless and helpless. How do I tell someone that I am afraid of myself? Why is this happening?

Katherine and I talk through the remaining forty-five-minute appointment then end by scheduling another one for next week. I walk back to my dorm room and climb into bed pulling the covers over my head. Maybe tomorrow will be better.

At the time of that appointment with Katherine, I didn't know that I had any sort of story to tell. I was obsessed with saying the "right" thing, and I couldn't figure out what that was for the life of me. Most of the time my thoughts spun faster than my mouth could get a hold of them so I just sat there, feeling stupid waiting for questions and lying believing my truth was too shameful.

So, beyond using narrative in medicine to form partnerships with patients and build bridges to overcome gaps in understanding, using narrative within the realms of mental health advocacy is also incredibly important and potentially healing. The social impacts that mental health advocacy groups have today are tasked with utilizing narrative in empowering ways to confront the oppression that mental illness has historically and culturally faced and developing ways to elevate a variety of mental illness narratives that reflect the reality of illness, treatment and recovery. At the same time, groups must be careful to not silence or favor one narrative type over the other.

Scholars today are studying chronic illness and disability narratives more than ever before (Cardillo, 2010). Richards (2008) in writing about his chronic illness experience of kidney failure states: "The expert on the lived experience of disability or illness is not the clinician, but the person experiencing disability or illness." This line of thinking is very different from the provider centered, biomedical narrative that has dominated and guided scholarship and research

for the last few hundred years. Not only is the reframe here starkly different, but also the power is acutely shifted from the providers and medical professionals back to the illness bearers. Such shifts of power are seen in narrative medicine methodologies. Cardillo (2010) describes illness narratives as ‘giving voice’ back to the ill and disabled. Which is essential because she reminds us, “Our society privileges those with undamaged bodies and minds to speak with a stronger voice than the voice of ‘others’” (p. 42). In creating this space and elevating the stories of mental illness we advocate for this shift and a change in what is considered ‘expertise’ and challenge the privileged ideologies of ‘undamaged’ and ‘strong’ bodies and minds.

However, even within the elevation of narratives, there is a social pressure to conform to a particular way of sharing stories in method, form, structure and content. Leimumäki (2012) found in studying chronically ill patients illness narratives that patients struggle to define their illness experience from the medical script given to them through medical charts. So even in sharing our experiences of illness, we rely heavily on what doctors have told us, diagnosis that have been made, medication and other elements of the dominant biomedical paradigm reinforcing that way of thinking about our bodies, minds and selves. Apart from what we include in our illness narratives, which narratives are highlighted, shared and elevated by society also speak to our desire to reinforce our current ideas about what it means to be sick and to suffer: that it will end. Cardillo (2010) writes: "Autobiographies of disability and illness may be constrained by strong cultural expectations that the narrative be one of inspiration and the triumph of an exceptional person over his or her (unacceptable) disability" (p. 529). This pressure to turn a negative into a positive reflects the desire or need for an individual to move out of struggle and illness and into triumph and health. This has negative implications for individuals whose experience does not fit this socially acceptable model.

Arthur Frank (2013) provides a framework for understanding the narratives of illness bearers through the lenses of restitution, chaos, and quest (Frank, 2013). The restitution narrative, he notes is in line with the dominant biomedical ideology and often sought out within the context of traditional western medicine. The restitution framework fits in with the western biomedical model seeking to control and fix what is broken or wrong. However, the reality is some people don't get better. For many people there is no "after" part of their story. This includes those with chronic illness, patients with terminal diseases and people whose bodies are left forever disfigured or changed. This demonstrates a tension between a society that knows and trusts the restitution narrative and the painful reality of some people's lives.

This restitution narrative also uses a chronological temporal framework for illness (Frank, 2013). To hear people talk about their recovery from mental illness because it common to hear it in a linear fashion noting progression, movement either forward or backward and using a frame of a road, path or journey. This, however, neglects the complex reality and experience that is living with and recovering from mental illness, reflecting the pressure to tell illness stories in certain ways.

Frank's chaos narrative is marked by hopelessness, being stuck and a lack of reflexivity. As a narrative, society, Frank notes, pushes away, silences and attempts to ignore chaos. In the chaos model, the individual narrates their experience as 'stuck in the doom' of their illness permanently (Frank, 1995). Despair, grief, and fear are hallmarks of the chaos narrative, having a high cultural association with weakness. Chaos is a familiar narrative that immediately follows the diagnosis of chronic illness. Frank (1995) highlights the importance of these narratives on a personal level for the individual suffering, to be heard and to deal with their feelings of fear and

distress. Despair and fear are emotions that narrators have to deal with as part of healing (Frank, 2013).

It is not uncommon for individuals experiencing mental illness to not experience or understand their lives in a linear fashion (Frank, 1995).

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“I’m going to stay on the phone with you while you get yourself ready.” My mom’s voice echoed through the phone to me. She feels so far away. I threw my heavy down comforter off my body and onto the floor.

“Okay, the covers are off.” I dictated to my mother.

“Good. Now, sit up.” I didn’t want to, but I also knew my mom would drive to Harrisonburg the second she thought I was too far in the ‘dark place’ and I didn’t need that. I sit up and plant my two bare feet on the shaggy green carpet that covered my dorm room floor.

“I’m out of bed.” Giving her another update.

“Good job sweetie.” She encouraged robotically.

“Now get some clothes on.” I begin looking around on my floor for something that smells remotely clean unable to remember the last time I did laundry. I grab some black sweatpants, my green sports bra and an old T-shirt from the lake where I used to lifeguard.

“Hang on Mom. I’m going to put the phone down while I get these clothes on.”

“Okay, sweetie. I’ll wait.” After slipping on the semi-clean clothes I return to my mother.

“Okay, I’m dressed.”

“Good job.” Her words stayed with me.

Good job. This is not a good job. This is pathetic. I needed my mother to talk me through getting dressed to make sure I get out of bed.

Good job, Erin.

“Do you have your socks and shoes?” Mom asked.

“Yeah. I’ve got them.” I set the phone down on the floor beside me as I slip on two mismatched socks and my gray sneakers. Picked the phone back up, grabbed my key and left the room.

“Okay. I’m walking down the hallway now, I’ll be outside soon.”

“Uh-huh” came from the other end of the phone. I could hear the banging of pots and pans. I guess it is almost dinnertime.

“I’m outside mom.”

“Good, now go for a walk and call me after okay? Being outside will be good for you.”

“Okay.”

“I love you, Erin.”

“I love you too mom.” As I hang up the phone I begin to wander around campus.

I watch people and smile as they pass by. I wave to two girls from world religion class then look away quickly. I wonder if they have noticed my absence.

What am I doing here? My chest tightens. Groups of people shuffle through the crosswalks, up and down stairs talking, laughing and living. Smells from the nearby dining hall are making my stomach growl. I stop and watch a puppy pee in the grass. I realized I stopped walking and was disrupting the flow of traffic.

I don’t belong here.

Dear God,

I wish I weren't alive. This is not how things were supposed to be. I'm exhausted. I try to be happy. I try to be pretty. I try to be smart. I try to be everything. I don't want to try anymore.

Everything aches as I swim in self-hatred. My brain reminds me “always a failure, never enough.” Secretly I long to be held as I keep everyone at a distance. Who am I supposed to be God? Why is this happening?

During this time, I lived my life in sixty-second intervals, and even the idea of thinking about the life before my current sixty seconds or after would add to my distress. I knew I was experiencing the world differently than my peers. I just had no conceptual framework or even model to compare or relate my experience to which increased my feelings of alienation and loneliness. Alison Torn (2009) addresses this discrepancy with linearity by using chronotypes. These chronotypes explain another way people experiencing mental illness might understand, experience and share their narratives.

The quest narrative, another typically linear narrative, involves a revelation of personal meaning found in the suffering and illness that the individual sufferer then feels called to share with others as communicative beings. The quest describes the illness as a 'journey' or experience that has transformed the person that the individual who has fallen ill has ultimately become. (Frank, 1995)

Quest stories are often the advocate's story because by nature they are narratives that turn illness into something meaningful by accepting the illness and using it for the moral good (Frank, 1995). The problem with quest stories is they can present the process as too clean and the transformation as too complete and they can deprecate those who fail to make something out of their pain and suffering. The reason understanding illness narratives and their uses in the context of psychiatry is so vital from an advocates perspective is because we gain a greater understanding of why mental illness has been stigmatized so harshly and what are some of the cultural challenges that we as society face when engaging in conversations about mental illness.

This can inform how we talk about mental illness, what stories we share and in which settings and emphasize the need for multiple perspectives and experience to be elevated within research, the health sector, through education and the like. Just because the primary stories we here are restitution and/or quest doesn't mean those are the primary experiences of individuals confronting the mental health system. That's actually incredibly doubtful.

I hear my alarm sound from across the room and roll over.

It can't be morning already, I think to myself. It takes me a few minutes to sit up as I stretch my arms up to the ceiling.

You can do this, Erin. It's just another day. My cat, Megan, brushes up against my leg as I stand in front of my dresser staring at my pill box, pop open the tab that says "AM" and throw the pills to the back of my throat gulping down water for a few moments.

Good job, Erin. It is a good job. I throw on clothes and feel comfortable on my body, clothes that won't make me want to pinch my fat all day long and wonder or obsess about the contents of my stomach. My heart races a little bit as I head to the kitchen.

I'm not hungry. Maybe I don't need it. I think for a moment.

Yes, yes you do. I respond to myself, grabbing a yogurt, granola bar and piece of fruit. I look over my calendar for the day as I eat, trying to measure how I'm feeling. *Maybe I'll cancel coffee with Sam today. I need to save energy for my doctor's appointments tomorrow and I'm working on getting that paper finished. I'm supposed to be social though, maybe I'll just push sleep up a little tonight. Oh, wait, that won't work I have to be up early tomorrow for work. I don't know I'll figure it out later. I'll have to see how I feel....*

I slip my shoes on and head to the car.

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