

“Maybe No One Is Really Crazy, but Everyone Is Just a Little Bit Mad”: Framing Experiences of Living with Madness in the TED Talk

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ABSTRACT

This article explores the victimizing experiences of individuals with mental illness using grounded inductive qualitative research methods, by extracting themes from 15 first-hand accounts of living with mental illness delivered on the TED Talks media platform. Emergent themes included (1) victimizing effects of the illness including the effects of medication and the effects of stigma, (2) normalcy, (3) the importance of help-seeking in the process of overcoming obstacles presented by mental health issues, and (4) victimization by others. We conclude that the speakers in our sample, even though they reflect an extraordinary level of functioning, still view themselves as what Becker (1991 [1963]) describes as outsiders, acting as moral entrepreneurs, crusading to normalize madness through a variety of strategies.

Keywords: stigma, mental health, victimization, moral entrepreneur, normalcy, madness

RÉSUMÉ

Le présent article explore les expériences de victimisation des personnes atteintes de maladie mentale au moyen de méthodes inductives de recherche qualitative établies qui permettent de dégager des thèmes porteurs de 15 récits de première main relatant ce que c'est que de vivre avec une maladie mentale. Lesdits témoignages ont été diffusés sur la plateforme médiatique TED Talks. Au nombre des thèmes émergents figuraient: (1) les effets victimisants de la maladie, y compris les effets associés à la médication et ceux de la stigmatisation; (2) la normalité; (3) l'importance de chercher de l'aide pour surmonter les obstacles que posent les problèmes de santé mentale; (4) la victimisation par les autres. Notre conclusion est que les

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locuteurs de notre échantillon, lesquels affichent un niveau de fonctionnement singulièrement remarquable, se perçoivent malgré tout toujours comme ce que Becker (1991 [1963]) considère être des marginaux, en agissant comme des entrepreneurs de morale et en poursuivant une croisade dans le but de normaliser la folie par une variété de stratégies.

Mots clés : stigmatisation, santé mentale, victimisation, entrepreneur de morale, normalité, folie

In any given year it is estimated that a fifth of Americans (NIMH, 2020) and Canadians (MHCC, 2017) will experience a mental health issue. Despite these high numbers, stigma continues to manifest in public conceptions of persons with mental illness (PMI), can become ingrained within institutions, and can be internalized and expressed by those living with the effects of mental illness (Corrigan et al., 2014). Goffman (1986 [1963]) describes stigma as “an attribute that is deeply discrediting” (p. 12). More specifically, it is a visible or hidden mark on an individual which decreases their moral status and is incongruous to any stereotype the observer may hold of an individual. Research demonstrates that PMI may not only suffer the ill effects of their symptoms, but also from the stigma associated with mental illness (Rusch, 2005). Public misconceptions of PMI include the view that PMI are dangerous (Corrigan & Watson, 2002; Rusch et al., 2005) needing to be cared for (Angermeyer & Matschinger, 2003; Rusch et al., 2005), and as having character flaws (Rusch et al., 2005). The media further perpetuates stigma by portraying those with mental illness as violent (Holland, 2012; Hyler et al., 1991, Wahl, 1995), unkempt, and abnormal (Wahl, 1995).

In addition, PMI can be more stigmatized than those with physical disabilities and are often seen as responsible for their illness (Rusch et al., 2005). Globally, more than 70% of individuals with mental illness do not receive healthcare services (Henderson et al., 2013). Specific reasons for lack of treatment include (1) lack of appropriate knowledge concerning how to self-identify mental illness, (2) not knowing how to access treatment, (3) prejudice against PMI (Henderson et al., 2013), and (4) an expectation of being stigmatized due to mental illness (Corrigan et al., 2014; Henderson et al., 2013; Rusch et al., 2005). Stigma may also be a significant barrier to receiving mental health services (Bharadwaj et al., 2017; Rusch et al., 2005). Some people may hide their behaviour due to internalized stigma (Bharadwaj, Pai, & Suziedelyte, 2017; Corrigan & Watson, 2002; Rusch et al., 2005), while others seem to be unaffected by stigma (Corrigan & Watson, 2002). In some cases, stigma can evoke anger in those subject to it, empowering them to change the system that manifests this discrimination (Corrigan & Watson, 2002). People living with mental illness may use normalization strategies to reduce this harmful stigma (Ekeland & Bergem, 2006). The purpose of this paper is to amplify the voices of 15 TED Talk speakers, who shared their experiences of living with mental illness, using grounded inductive qualitative research methods. This project builds on the emerging field within mental health research and activism that privileges individual narratives over psychiatry and psychiatric discourse (Menzies et al., 2013).

MAD STUDIES

Mad studies, coined in 2008 by Richard Ingram, is a movement that privileges experiential knowledge in understanding mental illness—or madness—over traditional psychiatric discourse and biomedical knowledge

(Faulkner, 2017). Experiential knowledge is “...specialized knowledge, grounded in an individual’s lived experience” (Borkman, 1990, p. 3), including those who are mad, have received or are receiving mental health services, or those who have survived other negative effects of mental illness (Faulkner, 2017). The goal is to ensure different perspectives come together for a comprehensive understanding of mental illness (Faulkner, 2017; Faulkner & Thomas, 2002) that de-centres the production of knowledge, challenging current paradigms that contribute to systems of oppression such as misogyny, racism, and ableism (Faulkner, 2017). Our research builds on mad studies by advancing experiential knowledge of being mad/living with mental illness, through privileging narratives as valuable sources of knowledge.

THE TED TALK

According to their website (TED, 2019a) Richard Wurman and Harry Marks developed the first *Technology, Entertainment, and Design* (TED) conference in 1984. This event was promoted as a new way of exploring “ideas worth sharing” that sought to progress knowledge and ideas without fundraising or imposing a religious or political agenda (TED, 2019c). Despite the first conference losing money, Wurman and Marks tried again in 1990, having a second conference in Monterey, California. The creators recruited scientists, philosophers, musicians, business and religious leaders, philanthropists and others to present knowledge in their respective fields (TED, 2019a) in less than 18 minutes (TED, 2019c). A successful expansion of this conference style presentation, known as TEDx, follows the same rules and values, but is licensed to other organizations, such as universities (TED, 2019c).

Proponents of TED and TEDx Talks argue that these presentations contain useful wisdom that we should take advantage of (Banker, 2013; Romanelli et al., 2014). In contrast, opponents take a skeptical view of this platform by expressing many criticisms. For example, although the speakers do not pay for entrance, travel, or accommodation, the audience entrance fee of a TED talk for non-presenters currently requires membership in the organization, conference fees ranging from USD\$3,000 to \$250,000 (TED, 2019d), and an application process due to limited spaces. This has the effect of making these events physically accessible only to those who can afford membership and are deemed eligible for the conference, yet digitally accessible to a much wider audience via their social media platform (Robbins, 2012). Second, many argue that in the TED platform complex ideas are over-simplified, diminishing their full understanding and impact (Romanelli et al., 2014; Whelan, 2014). Finally, Denskus and Esser (2015) argue that TED Talks replace real social action because the audience feels like they contributed to real change without active participation. Although TEDx Talks appear to be more accessible—as they are free to attend—similar elitist criticisms apply because they are associated with universities and require special knowledge of locations, timing, and presentations (Clark, 2014; TED, 2019b). Despite these criticisms, this paper gains valuable insights into moral entrepreneurial thinking around lived experience and issues of mental illness using presentations on this platform.

NORMALCY AND THE MORAL ENTREPRENEUR

Goffman (1966; 1983; 1986 [1963]) describes *normalization* as a strategy used by stigmatized populations to appear normal in the attempt to diminish stigmatization. Recent theorists have used Goffman’s

definition of normalization to describe how other populations try to appear normal to avoid stigma, discrimination, and to feel safe in the social order (Deatrick et al., 1999). Research shows that those with madness, and the families which surround them, seek normalcy for themselves through a variety of mechanisms. Orem (1995) argues that PMI may try to act “normal,” using normalizing vernacular, and acting normal in other ways. Orem offers that “identifying and attending to deviations from one’s structural and functional normal...” (p. 193) are strategies that people use to promote a sense of normalcy for themselves.

Rose, Mallinson, and Walton-Moss (2002) found that families helped members with mental illness be as “normal” as possible and adjusted their own ideas of normalcy to view their loved one as “normal.” Persons with mental illness also normalize their illness by using more common illness vernacular. For example, according to Pickens (1999), one PMI described their bouts of mental illnesses as “I got sick” (p. 235). Medication was also used as a normalizing strategy in this way: “It’s like taking medicine for high blood pressure” (p. 237). Other specific normalizing strategies identified in the Pickens study used by those labelled as PMI include (1) having culturally normal belongings and experiences, (2) engaging in substantive activities, (3) not doing harm to self or others, (4) being “well, safe, free, and independent” (p. 235), (5) finding work or other meaningful activities, (6) getting groceries independently, and (7) acquiring meaningful relationships.

In his seminal work, *Outsiders*, Becker (1991 [1963]) offers that often groups form as the result of shared experiences and values which they perceive to be unusual or outside the experiences of others. A group with shared values can come to see themselves as *outsiders* to mainstream culture. Likewise, those in the mainstream may see people who share certain experiences and values as outsiders. Outsiders can become *insiders* by creating stronger social ties with various groups that they wish to identify with using several strategies. In other words, after PMI have self-accepted and achieved normalization for themselves, they may seek to change others’ definition of normal, via moral entrepreneurship, in order to normalize mental illness on a wider, more societal, level.

Platforms such as TED Talks are unique in that they give a powerful stage for selected budding moral entrepreneurs to share their narratives. Becker (1991 [1963]) identified moral entrepreneurs as individuals who progress societal values and moral standings to more clearly match their own. In this way, moral entrepreneurs work to persuade others to believe in and support their cause. Traditionally, medical professionals such as psychiatrists, psychologists, and medical doctors have been the moral entrepreneurs of mental illness (Scull, 1975), shaping early public perceptions. More recently, celebrities are engaging in moral entrepreneurship around mental health by sharing their experiences, using their reputation as a platform to reduce stigma (Eaton, 2009). The message communicated usually seeks to normalize mental illness and promote discussion and acceptance.

METHODOLOGY

In this study, a sample of TED Talks were gathered from TED.com. The inclusion criteria were (1) speakers must be giving first-person accounts of living with chronic mental illness experience, and (2) were diagnosed with disorders as listed in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition ([DSM-5] American Psychiatric Association [APA], 2013). The speakers self-reported living with a mental illness for an indefinite and extended amount of time, which we define as “chronic.” Examples of reasons for

excluding a video included the speaker talking about a friend with a mental illness, the speaker only advocating for new detection, treatment methods, and/or prevention of a disorder, and the disorder being temporary. Searches on the website TED.com involved entering all listed disorders in the DSM-5 table of contents (APA, 2013). Due to the initial limited results, we decided to remove words that hindered the searches, such as “disorder,” “spectrum,” and “related,” which then resulted in a larger sample. Finally, TEDx speakers were not included in the sample to control for external conditions, as TED and TEDx environments can be very different kinds of events. A total of 15 speakers matched criteria and are listed in Table 1. All participants self-identified as living with at least one of six diagnostic categories of mental illness: autism, depression, anxiety, schizophrenia, bipolar depression, and attention-deficit-hyperactivity-disorder (ADHD).

While in the public domain, there was ethical consideration given to whether to include the speakers’ names within this study. An issue identified with current knowledge production and activism is that those with experiential knowledge are often silenced and excluded (Faulkner, 2017). A question emerged as to whether to amplify the voices of respondents (Einwohner, 2011), or protect their identities. In line with practice by Einwohner (2011), who ultimately included the names of holocaust survivors in her research, we decided to include the names of the presenters, who self-identified and self-disclosed their mental illness status on the TED platform. As researchers, we are seeking to amplify their message given their very public and deliberate choice to share their story via this very popular medium. It is also possible that the names offered by presenters may, in some cases, be pseudonyms. We have included the names, as identified by presenters, and links to their videos to provide access to their original words in full, as there can be various interpretations of their narratives, with this paper being one such example.

Using grounded, inductive, qualitative research methods, videos were watched initially without the formation of any predetermined themes or concepts (Charmaz, 1983). Subsequent viewings generated themes consistent with many of the presentations. Four major themes were identified: (1) victimizing effects of the illness including the effects of medication and stigma, (2) normalcy, (3) the importance of help-seeking in the process of overcoming obstacles presented by mental health issues, and (4) victimization by others. These themes are not exhaustive but highlight significant patterns that emerged in the dialogue of speakers. Table 2 outlines these themes with associated keywords and phrases that indicated theme presence.

Table 1
Sample of Selected TED Talk Videos, Including Name of Speaker, Reported Diagnoses, and Social Media Link

| Name | Diagnosis | Year | Link |
|------------------|---------------|------|---|
| Nikki Allen | Depression | 2017 | https://www.ted.com/talks/nikki_webber_allen_don_t_suffer_from_your_depression_in_silence |
| Becky Blanton | Depression | 2009 | https://www.ted.com/talks/becky_blanton_the_year_i_was_homeless |
| Kevin Breel | Depression | 2013 | https://www.ted.com/talks/kevin_breel_confessions_of_a_depressed_comic |
| Sangu Delle | Anxiety | 2017 | https://www.ted.com/talks/sangu_delle_there_s_no_shame_in_taking_care_of_your_mental_health |
| Alix Generous | Autism | 2015 | https://www.ted.com/talks/alix_generous_how_i_learned_to_communicate_my_inner_life_with_asperger_s |
| Temple Grandin | Autism | 2010 | https://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds |
| Rosie King | Autism | 2014 | https://www.ted.com/talks/rosie_king_how_autism_freed_me_to_be_myself |
| Joe Kowan | Anxiety | 2013 | https://www.ted.com/talks/joe_kowan_how_i_beat_stage_fright#t-4190 |
| Eleanor Longden | Schizophrenia | 2013 | https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head |
| Jessica McCabe | ADHD* | 2017 | https://www.ted.com/talks/jessica_mccabe_failing_at_normal_an_adhd_success_story |
| Sherwin Nuland | Depression | 2001 | https://www.ted.com/talks/sherwin_nuland_on_electroshock_therapy |
| Elyn Saks | Schizophrenia | 2012 | https://www.ted.com/talks/elyn_saks_seeing_mental_illness |
| Andrew Solomon | Depression | 2013 | https://www.ted.com/talks/andrew_solomon_depression_the_secret_we_share |
| Joshua Walters | Bipolar | 2011 | https://www.ted.com/talks/joshua_walters_on_being_just_crazy_enough |
| Matthew Williams | Autism | 2015 | https://www.ted.com/talks/matthew_williams_special_olympics_let_me_be_myself_a_champion#t-134481 |

*Attention Deficit Hyperactivity Disorder

Table 2
Themes of TED talk Speakers, Keywords and Phrases Used to Reinforce Themes, and Frequencies

| Theme | Subtheme | Keywords/Phrases | # of videos with the themes | Total appearances in full sample |
|---------------------------------------|-------------------------------|---|-----------------------------|----------------------------------|
| Mental illness as victimizing | Symptoms | Painful experiences, being broken, feeling hopeless | 15 | 101 |
| | Medication | Medication sometimes necessary, painful side-effects, inadequate medication | 4 | 11 |
| | Stigma | Shame, lack of understanding, discrimination, scared of others' thoughts, internalized stigma | 12 | 57 |
| Normalcy | Seeking normalcy | Trying to appear normal, not wanting to take medication due to stigma | 8 | 23 |
| | Mental illness as commonplace | good aspects of disorder, famous people have same disorder, disorder is a sickness, using statistics, inspiring others to 'shatter the silence', medication is not a weakness | 14 | 92 |
| Help-seeking | None | Recovery, relapse, support from friends and family | 9 | 49 |
| Victimizations by others | None | Sexual/physical abuse, treated as criminal, bullied | 7 | 27 |
| Total incidents disclosed by speakers | | | | 360 |

RESULTS

As indicated in Table 2, themes are listed in order of frequency of appearance within the sample. Below we discuss our findings in order of most prevalent to least prevalent thematic presence.

Mental Illness as Victimizing

Persons with mental illness often experience very distressing and painful symptoms of their illness. However, outsiders often underestimate the devastating effects of medication and stigma.

The effects of symptoms. All PMI in our sample spoke about negative aspects of living with madness. Following the principles of Mad Studies, this section highlights what the presenters self-identified as symptoms, rather than limiting it to symptoms expressed in the DSM-5. Although not the worst part of their respective psychological disorders, symptoms were often reported as very painful. Negative symptoms of mental illness experienced by these presenters included “writhing in agony” and having a “shattered” mind (Saks, 2012, 4:50), feeling “hopelessness, humiliation, and despair” (Longden, 2013, 10:16), fearing yourself (Breel, 2013, 6:12), being “angry and frustrated” (Williams, 2015, 10:16), and experiencing a “sense of doom” (Allen, 2017, 6:00). Paradoxically, medication designed to ease their respective symptoms was cited as one of, if not the worst, aspect of dealing with their illness.

The effects of medication. Although sometimes mentioned as a necessity (McCabe, 2017, 2:05, 10:40, 11:10; Saks, 2012, 3:35; Solomon, 2013, 23:55), medication often had unfortunate consequences of illness treatment. Although medication was necessary for Jessica, a woman with ADHD, it was not enough to maintain a “normal,” “successful” life (McCabe, 2017, 10:40). Nikki, a woman coping with anxiety and depression, reported using meditation, yoga, a healthy diet, and a therapist to control her symptoms, rather than medication (Allen, 2017, 1:00). For Alix, living with autism, medication caused hallucinations, a loss of 19 pounds, anemia, and suicidality (Generous, 2015, 6:20). Others in the sample viewed medication as a personal necessity. Elyn, living with schizophrenia, offered that she would not have been around to give her talk without the good combination of medication and psychologists (Saks, 2012, 3:18). In addition, there is a consensus among these participants that medication is sometimes required for symptom control. The overall message is that it is ideal to avoid medication if the individual can live a fulfilled life without it but there is no shame in accepting medication.

The effects of stigma. Within these recordings, indicators of stigma manifested through how speakers perceived others’ responses to the PMI, and how the speaker had internalized stigma. First, speakers who identified stigma as an issue noted that strangers, family, and close friends did not always demonstrate understanding. Specifically, five of the speakers articulated that they were scared to expose or accept their mental illness for fear of stigma (Allen, 2017, 5:00; Breel, 2013, 6:37; Delle, 2017, 7:56; Longden, 2013, 13:45; Saks, 2012, 5:40). They reported that stigma manifested in the form of social exclusion and discrimination, such as being called names and being excluded from groups. Presenters noted that friends used the following words to describe them: “insane” (Longden, 2013, 10:55), “invisible” and “retarded” (Williams, 2015, 12:53), “disadvantage[d]” (Generous, 2015, 4:00), “demons” (King, 2014, 4:25), and “gravely disabled” (Saks, 2012, 7:03). Presenters did not identify with these traits, resulting in feelings of exclusion and being judged unfairly. These examples demonstrate how secondary labels associated with outsiders’ understanding

of mental illness can lead to the victimizing effects of stigma and discrimination from strangers and people close to them.

Furthermore, speakers reporting on the effects of stigma and mental illness also noted that this often prevented them from sharing their struggles with others. In other words, the individual experiencing mental illness had internalized their symptoms as deviant to the point of preventing them from speaking up for fear of stigma. Some speakers (Allen, 2017, 5:40; Delle, 2017, 6:26; Solomon, 2013, 24:20) in our sample narrated as part of their personal stories that they did not come forward immediately because they perceived their mental illness as a weakness in some way. For example, Andrew, a man who identified as having depression, refused to take medication for a long time because it made him question his strength (Solomon 2013, 24:20). Sangu, a man reporting severe anxiety, feared being viewed as “the mad man” on the street because of his illness (Delle, 2017, 6:26). The stigma was so ingrained that it prevented him from seeking help for fear of admitting that he was not normal and had an illness that required treatment for symptom control, regardless of side effects.

Normalcy

All presenters alluded to, or overtly expressed, a need for normalcy, indicating that they desired others to view them as normal. Although many of the speakers did not directly verbalize their experiences as normalizing, we interpret many of their actions, as with the Pickens (1999) study, to be part of the normalizing process. In particular, normalizing appears in two forms: seeking normalcy in their own lives and, second, showing their audience that mental illness is commonplace by pointing to others as sharing their experiences.

Seeking normalcy. Presenters reported that after they identified their symptoms, and understood there was something “wrong” with them, they often employed strategies to manage how others perceived them. While most in this study reported trying to appear normal as an illness management strategy at some point in their illness experience, specific strategies varied. To illustrate, when symptoms first appeared, several presenters (Allen, 2017; Breel, 2013; Longden, 2013) tried hard not to appear abnormal within their social networks because they did not want to evoke fear or discomfort in others, which can lead to stigma. One of their strategies reported was trying to appear happy to help maintain the illusion of normalcy by masking the negative effects of the illness. For example, Eleanor, said she “felt empty inside” but was “pretending to be happy” (Longden, 2013, 13:20). Kevin, a man reporting depression, felt “afraid for people to see [him] for who [he] was” (Breel, 2013, 6:37), causing him to hide his feelings of suicide through being active in school events. Nikki said she “put a smile on [her] face” (Allen, 2017, 4:21) in order to appear happy and normal.

Mental illness as commonplace. Often those with more experience as a PMI in this study used normalizing strategies to express how mental illness does not make a person abnormal. Normalization is performed by moral entrepreneurs by changing the definition of normal (Becker, 1991 [1963]) to include those with mental illness. Other studies have used the process of normalization to examine how other deviant realities (e.g., former marijuana use, living with physical disabilities) have been increasingly normalized in society (Hathaway et al., 2011). Joshua sought to normalize his symptoms of manic depression by suggesting that “maybe no one is really crazy—but everyone is just a little bit mad” (Walters, 2011, 0:41). In this way, being

identified as a person with mental illness is comforting because it normalizes the experience as something shared by many others.

Another strategy mentioned by speakers is to fully accept the disorder and present it as a beneficial tool rather than a disability. Alix and Rosie appreciate their autism because it gives them other abilities such as a “vivid imagination” (King, 2014, 4:07) and “so much energy” (King, 2014, 2:41). Alix (Generous, 2015) describes her autism as “a gift” (6:34) that allows her to be “highly focused” (9:03), have “rich ideas” (5:22) and “allow[s] [her] to think innovatively” (3:48). Similarly, Eleanor, identified her auditory hallucinations as “insights into solvable emotional problems” (Longden, 2013, 6:31) and found them somewhat comforting and helpful. Kevin said he was grateful for his depression because it reminds him that “[his] pain ... has given [him] perspective and [his] hurt has forced [him] to have hope...” (Breel, 2013, 2:01).

Speakers in this sample sought to normalize madness to their audience through the strategy of expressing the normal activities they were engaging in. Eight out of 15 speakers framed their education and/or career as major accomplishments (Blanton, 2009, 1:10; Generous, 2015, Saks, 2012). To illustrate this point, one of the speakers emphasized she was a writer who had won awards (Blanton, 2009, 1:10). Elyn received applause after mentioning she is a professor—a high status career (Saks, 2012, 2:10). Alix and Nikki emphasized that they were accepted into university (Generous, 2015, 9:50; Allen, 2017, 5:30), and Alix noted that she had started her own company to help others with autism communicate more effectively to release their potential (Generous, 2015, 3:25).

Speakers also normalized their experiences by comparing their mental illness to famous individuals who experience similar symptoms. Alix compared herself to Emily Dickinson, Jane Austin, Isaac Newton, and Bill Gates, who also had, or are currently living with, autism (Generous, 2015, 1:52). Joshua compared himself to Mozart, Beethoven, and Van Gogh who also suffered from symptoms of manic depression (Walters, 2011, 2:00). Temple demonstrated the necessity for different kinds of minds by saying Einstein, Nikola Tesla, and Mozart all had autism (Grandin, 2010, 18:55).

Whether self-labelled or labelled by others, naming people who exhibit unusual or bizarre behaviours as “sick” is perhaps the most common normalization technique. Many speakers (Allen, 2017, 2:42; Breel, 2011, 2:35; Delle, 2017, 1:15; Grandin, 2010, 19:10; Longden, 2013, 6:37, 2:33; McCabe, 2017, 10:20; Solomon, 2013, 5:00) in our sample appeared to ascribe to the medical model, whether mental illness was attributed to biological (e.g., genetics, hormone imbalances, etc.) or exposure to environmental (e.g., harmful chemicals, socially learned behaviour, drug use, etc.) factors. Symptoms were presumed to be the result of ill health or “being sick.” This reframing of their experiences as sickness or illness was used by some speakers as a tool, offering that it takes away feelings of guilt and shame. Kevin said that if you have depression “you are sick, not weak” (Breel, 2013, 2:34). Therefore, as a sickness, no one should be ashamed to seek help, implying help seeking was a normal part of maintaining good health and is a sign of strength, not weakness.

The Importance of Help-Seeking

Three of the speakers identified that initially they did not seek help for fear of the reaction of others. For example, Eleanor (Saks, 2013) hid the fact she was “deeply unhappy, insecure, and mentally frightened” (13:40) for fear of others’ perceptions. Recall that Kevin (Breel, 2013) initially hid his illness from everyone,

including those who may have been able to help because of his crippling fear of exposure and stigma. Sangu (Delle, 2017) was initially anxious about telling his friends about his diagnosis and reported losing them after his disclosure (2:46). To eventually seek help, the fear of the effects of stigma had to be overcome.

Although there are different opinions about what kind of help is better, all presenters speak positively of getting help in some form. Although some TED speakers did not mention medication at all (Blanton, 2009; Delle, 2017; Grandin, 2010; King, 2014; Kowan, 2013; Walters, 2011; Williams, 2015), or reported that it created more negative than positive consequences (Allen, 2017, 1:00; Generous, 2015, 6:10; Longden, 2013, 5:47, 10:00; Nuland, 2001, 11:30), several presenters needed both medication and other techniques to manage symptoms (McCabe, 2017, 11:40; Saks, 2012, 3:35; Solomon, 2013, 23:40). Seeking help was often the turning point in the participant's disorder, although recovery was either not sought, for those with autism (Generous, 2015; Grandin, 2010; King, 2014; Williams, 2015), or signified symptom management rather than eradication of symptoms (Allen, 2017; Breel, 2013; Kowan, 2013; McCabe, 2017; Solomon, 2013; Longden, 2013; Saks, 2012). Nikki said that getting assistance has helped her manage her symptoms and offered that "...with help [you] can heal." (Allen, 2017, 1:10). Elyn expressed that she would be dead without help (Saks, 2012, 3:14). Almost everyone spoke about how they needed to get help, and many advised anyone watching with mental illness to seek help.

Getting help was often not possible without the support of friends, family, or support groups who shared the same diagnosis. A third (5/15) of speakers specifically mentioned the importance of support by friends and/or family (Allen, 2017, 2:07; Longden, 2013, 6:57; McCabe, 2017, 11:45; Saks, 2012, 3:15; Solomon, 2013, 24:00). The support gave them a reason to get well and was a source of encouragement. Eleanor spoke of how her friends, family, and doctor never gave up hope on her recovery: "But together they forged a bond of courage, creativity, integrity, and an unshakable belief that my shattered self could become healed and whole" (Longden, 2013, 6:57). This speaker identified a positive link between mental illness and personal supports which has been supported by other research (Piat et al., 2011).

Victimization by Others

Individuals with mental illness often have a history of victimization and an increased chance of being further victimized (Friedman et al., 2009). Specifically, in our sample this applied to two individuals with schizophrenia—supporting research that found that schizophrenia is the most criminalized mental illness (see Lamb & Einberger, 2011), putting them at higher risk for victimization. For example, Eleanor identified her schizophrenia as a coping mechanism for a history of abuse. Eleanor's mental illness was associated with further victimization in the form of verbal, physical, and sexual abuse (Longden, 2013, 8:42). Elyn was tied to a hospital bed, causing her pain and dehumanization (Saks, 2012, 8:15). Although no one else reported feeling criminalized, they expressed feeling the weight of stigma and the need for normalcy.

DISCUSSION

All stories collected in this study have in common the shared experience of unlocking human potential of individuals living with mental health issues or madness. These speakers exemplify what Becker (1991 [1963]) would describe as moral entrepreneurs, holding specialized knowledge and the ability to clearly

and effectively communicate their ideas to a wider audience in order to effect change. Becker observed that PMI view themselves as *outsiders* sitting on the periphery of more common social experiences. Likewise, they see those who do not live with mental illness as outsiders to their lived experiences. What is interesting about this sample is that they all have used the normalizing strategy of sharing their stories of mental illness in an atmosphere of acceptance and understanding, through their use of the TED platform. Their stories on this platform seek to redefine experiences and perceptions of mental illness on a global scale.

Specifically, these presenters offer an alternative to the narrative of mental illness as negative, where people “suffer” and that they and their illnesses are abnormal, even though they acknowledge it can be painful at times. The normalcy theme has been shown in not only theories related to labelling (Becker, 1991 [1963]) and stigma (Goffman, 1986 [1963]) but also in more recent studies examining how labels and stigma are addressed by PMI and their families (Haug et al., 2009; Rose et al., 2002). If being perceived as abnormal leads to stigma, the speakers in this sample argue that stigma can be decreased by acknowledging that we are all different, that mental illness is quite common, and therefore those living with mental illness are normal. This is a rational assertion, if national statistics on the prevalence and lifetime exposure to mental illness (MHCC, 2017; NIMH, 2020) are taken at face value.

The symptoms, experiences, and healing process expressed by these presenters reflect how first-person narratives are essential knowledge for combatting current psychiatry models (LeFrançois et al., 2013). These same authors note that psychiatric models (re)produce neoliberal ideals, such as privatization, consumerism, fiscal restraint, privileging the free market, and wholesale retrenchment of social services. Neoliberal principles seep into many aspects of life, such as ways to categorize, understand, and treat people with mental illness. It is no coincidence that predeterminants of health are worse in societies where there is a larger gap between the rich and poor (LeFrançois et al., 2013). The presenters examined in this article sought to progress values that add to the pushback, as progressed by Mad Studies, of the neoliberal psychiatric model approach to mental illness. Examples presented by the TED Talk speakers include alternative measures of success, seeing medication as often harmful and unnecessary, the immense stigma and isolation of those with madness, and difficulty accessing services.

One of the ways in which this is done by these moral entrepreneurs is to redefine or re-label madness as a health issue, thereby medicalizing their experiences of deviance (Lazarus, 1981). According to Wright, Jorm, and Mackinnon (2011), stigma could be the result of the effectiveness of label application by the self or others. We use labels to categorize our thinking but, in some cases, labels may be damaging as they allow a mechanism for individuals to discredit others (Becker, 1991 [1963]). The stigma created by labels has strong potential to damage people’s self-esteem and self-efficacy (Link, 1982; Schrank et al., 2012). What is interesting is that these speakers seek to move the needle, on a global scale, by encouraging the audience to accept the medicalization of their experience as within the normal spectrum of illness. For the most part speakers, in this sample, offered that their mental illnesses are, in many ways, not any different than those who suffer from long-term, physical ailments. Therefore, they collectively offer those social perceptions of mental illness and the programs that service this community should reflect this new normal in understanding these issues.

In line with Pickens (1999), all the measures of success used by these very eloquent orators appear to perpetuate and maintain the status quo. These individuals, who are completing school or obtaining a

prestigious career, symbolize normality and the ability to be successful by common Westernized social standards. Measures of mainstream success were used to prove their intelligence and worth to outsiders. In other words, when someone with mental illness achieves mainstream measures of success it has the potential to lessen the gap between PMIs and non-PMIs. While it is valuable to acknowledge that those living with mental illness can achieve ambitious mainstream accomplishments, this may not be guaranteed or possible for everyone, including those living with a mental illness. Identifying alternative measures of success, such as maintaining a sense of independence in some aspect of life, having income above the poverty line, maintaining hope and optimism, and having positive relationships (Schrack et al., 2012), could be useful strategies moving forward.

Although respondents reported that stigma did garner negative responses, such as initially masking or hiding symptoms and not seeking help, eventually these speakers significantly lessened the effects of stigma by sharing their mental health concerns with friends or family. Speakers reported early illness management strategies of pretending to be happy to appear normal to avoid being stigmatized—seeking to pass as an “insider” of larger social groups. After they gained a sense of normalcy, they were able to use other normalizing activities, such as accomplishing socially acceptable goals, and seeking help. One of the significant areas where these speakers differ is that they, then, were empowered into activism on the world stage via the TED platform, advocating for their own, and other PMIs’ needs for better services and reduced stigma around this issue. Their very ability to secure a spot on this platform, given the challenges of qualifying and expense, suggests that these speakers may, in fact, be exceptional, with a disease process they argue as common.

Our results are comparable to other similar studies, with some substantial differences. Other studies found that PMIs aim to hide what makes them different, seek normalcy in their lives in a variety of ways (Lally, 1989; Shepherd et al., 2012), and identified social support as very important (Michalak et al., 2006). The originality of our research is that it examines individuals living with madness who are moral entrepreneurs. As such, in addition to confirming previous themes of support, stigma, and seeking normalcy, these presenters also highlight how those with a mental illness share common experiences when compared to those without it, in various areas related to education, occupation, abilities, strengths, and value.

LIMITATIONS

Delivering a presentation on the global platform of the TED Talk series can be done by only a very few who are willing, capable, and able to gain access to this platform. One must be familiar with the platform, have a talk that the conference organizers agree is “an idea worth sharing” (TED, 2019c), have the skills, training, and confidence to share that idea, and large fees may have to be paid for the privilege to share. We realize that this sample of speakers is a highly specialized and supported PMI group who are able to work with this platform. In addition, most are university educated and have achieved success in their field. This, of course, is not the case for many of those with more severe symptoms of mental illness. The prognosis of such disorders is not always perceived as positive by the receiver, their support network, and/or the wider public. We argue, however, that the narratives presented by these speakers are rich with information about living with mental disorders of various kinds, and the messages that they offer are worth sharing and are valid and worthy of study. The benefit of using this sub-sample is to hear articulate, in-depth stories of how mental health programs are helping or hindering the healing process. This may help with mental health initiatives.

Second, this research was limited to a small, yet exclusive, sample of talks from a single platform. This was done to preserve homogeneity of external factors about the sample, given the series has a clearly defined set of parameters that are suitable for exploration. Future research should look to expand sample sizes by exploring other platforms used by those seeking to share their experiences of madness, including other online talk/lecture series as well as those whose parameters are produced solely by those who are mad such as blogs and vlogs. We encourage further research using these new technologies to capture more diverse marginalized voices. The articulate and reflective people who are mad in this sample have the ability and knowledge to offer invaluable knowledge to researchers and front-line best-practices to provide more experienced, intuitive, compassionate and, perhaps, effective mental health programming.

Third, we acknowledge that the speakers may have molded their talks to meet the platform they are sharing it on. Ludewig (2017) noted that these Ted Talks are highly structured, often with presenters who are coached to give that informal appearance so characteristic of TED Talks. This researcher also notes that not all talks are made available on their various platforms suggesting that some ideas are not “worth sharing,” for any number of reasons. As a result, those who actually attend the conferences may have access to more talks than are made available on their public platforms. One restriction may be that the organizers only publish talks that align with their ideological outlook of innovation and education as a form of infotainment and enterprise. Those ideas which do not fit into these broad directives (not inspiring, not entertaining, etc.) may be excluded from the non-conference participating public. Despite this limitation, Ludewig further argues that Ted Talks are an emergent discursive platform that can provide valuable information, such as the useful information provided by participants in our analysis. As such, in using these talks as a data source, we agree with Banker (2013) and Romanelli, Cain and McNamara (2014) that these presenters provide wisdom, that we should take advantage of, to glean information that is useful in generating possible new and emerging patterning, further discussion, and impetus for further research, among many other uses.

Finally, qualitative research remains a subjective process that is imperfect (Schutz, 1994). We are conscious that the subjective experiences of mental illness as an umbrella term may not encapsulate the diversities that exist within. Further, we want to emphasize that our categorization of themes and subthemes are informed by our own biases and life experiences. Therefore, this research is one interpretation of the diverse experiences of these speakers. We encourage readers to listen to the stories as told by those living them for their direct expertise.

CONCLUSION

We sought to participate in the Mad studies episteme by privileging and amplifying the voices of those living with madness (Faulkner, 2017; LeFrançois et al., 2013; Menzies et al., 2013). The goal is to progress more effective treatment and programming for those who live with mental illnesses through first-person narratives. Finding first-hand accounts of the experiences by PMIs have, historically, been challenging. Newer platforms provided by social media are changing this landscape, putting more of these stories into the public domain. This research adds to the field of mental health and victimology research by adopting a victim-centred perspective, using personal stories of mental health advocates and moral entrepreneurs who have achieved a high level of success as people living with mental health issues. Understanding these stories of achievement and overcoming challenge may be useful for individuals who, and support networks which,

may be less articulate in changing the level of stigma around mental illness. This, in turn, may serve to help create a more normal experience with more effective service provision for PMIs. Even with this small sample, what becomes evident is that the one-size-fits-all approach to mental health services may not be an effective strategy for dealing with mental health, even among those who appear to have similar symptoms.

Overall, the speakers are attempting to redefine what it is to live with madness on a global scale. Using their charismatic skill set and wisdom, their collective goals are to change public perception of mental illness experience in order to reduce stigma and increase acceptance by both outsiders and insiders. Specifically, the participants use normalizing strategies to reduce stigma associated with madness, as they all have perceptions of being stigmatized by others as well as recounting actual, sometimes self-inflicted, victimization. Successful implementation of normalization strategies bridges the gap between experiences and perceptions of normal and abnormal—creating commonalities, blurring social boundaries between insiders and outsiders and, as such, promoting social values of inclusivity and acceptance over stigma. As one speaker so eloquently stated to others who may share their experience: “You are different, you are beautiful, and you are not alone.” (McCabe 2017, 16:15).

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