

I Wish I'd Been Diagnosed with Cancer: The Stigma of Mental Health

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Abstract

The author explores how stigma from having a mental health diagnosis can impact the person and those around them. Through both personal and historical contexts, the author examines the effects of social rejection on individuals, families, work opportunities, and personal relationships. There is a clear need for a shift towards a more compassionate and understanding approach to mental health. Dodds argues that open discussions can encourage people to seek help and improve treatment.

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“I wish I had been diagnosed with cancer; at least then people would care. Instead, no one wants to talk to me anymore” (Dodds, personal communication, November 2019). This was a comment from my husband after his release from a psychiatric hospital ward following his first involuntary hospitalization due to psychosis from untreated bipolar disorder. This was the first time he was diagnosed with a significant mental health condition (MHC). However, the manner in which the diagnosis was made, his awareness of the social implications attached to his diagnosis, along with the immediate negative responses of family and friends, made him very aware of the ongoing stigma he would face both socially and professionally. Actor Margot Kidder made a similar comment in 2012 when speaking of the fallout from her personal 1996 mental health episode. Kidder experienced a bipolar mania episode with psychotic features. This event continued to have an impact on public perception of her as a person and an actor and cost her work in the film industry due to this idea that her MHC was permanent (Yanos, 2018). “[I]f I were a cancer patient, I would today be considered cured – I haven’t had [a psychotic] episode in 14 years” (Yanos, 2018, p. 1). Mental health stigma contributes to the disability experienced by those dealing with a MHC as well as negatively impacting the families of those diagnosed.

History of Mental Health Stigma

Those diagnosed with a MHC in earlier times experienced an equivalent feeling of stigma and rejection to that which my husband faced. The following poem, written by John Clare (1848), while more eloquently expressed, mimics the comments of my husband well.

I AM: yet what I am none cares or knows

My friends forsake me like a memory lost...

And e’en the dearest – that I loved the best –

Are strange – nay rather stranger than the rest (as cited in Yanos, 2018, p. 24)

Clare, a British poet, spent 27 years incarcerated in various institutions in the early 1800’s (Yanos, 2018). This poem clearly elucidates the stigma he felt, the rejection of even those he held dear and who he thought he was dear to.

Similar to the experiences of Clare, the prominent dermatologist Dr. Perry Baird (1903–1959), institutionalized for episodes of psychotic and manic behaviours, made the following comments about his experiences:

Once one has crossed the line from the normal walks of life into a psychopathic hospital, one is separated from friends and relatives by walls thicker than stone; walls of prejudice and superstition ... The brutalities that one encounters in state and city psychopathic hospitals must be the by-product of the fear and superstition with which mentally ill patients are regarded. (Yanos, 2018, p. 24)

Mental health stigma is not a new or recent issue. Evidence of MHCs appears throughout the history of humankind; however, the response of different societies has varied (Yanos, 2018). There is evidence that in some regions at certain times in history, such as the Arctic where Inuit people cared for those with MHCs and did not see them as burdens, nor regarded them as dangerous and those with MHCs experienced little or no stigma (Yanos, 2018). Unfortunately, there is also ample evidence that this was not always the case. In ancient Greece, MHCs, referred to as “madness”, was thought to be caused by supernatural forces, by The Gods and was a sign that an individual had behaved in such a way as to deserve their curse of insanity. (Yanos, 2018). Madness was a punishment and the subsequent stigma imposed by society was deserved. This stigma consisted of ridicule, those with MHCs were treated with condemnation, they were avoided, and people even spat at the sight of those so afflicted (Yanos, 2018). Romans appeared to have had a similar view with subsequently similar stigmatizing behaviours directed at those afflicted with madness (Yanos, 2018).

Ancient Chinese beliefs of the cause of madness were drastically different, they took a biological perspective of MHCs. While this was a drastically different view of the cause of the conditions and the odd behaviours it engendered, this did not result in significantly less stigma of the those afflicted. In fact, it was believed MHCs brought shame to one’s family and could even taint their reputation when it became known a member of the family was displaying signs of madness (Yanos, 2018).

In Europe and North America in the 1700’s there was a shift away from the idea of supernatural influences on madness. However, stigma remained and treatment of those with MHCs did not improve. Individuals who displayed symptoms of madness were all assumed to be lesser and were treated as such (Yanos, 2018). Sadly, while our understanding of the causes of MHCs have evolved throughout the 19th and 20th centuries, the stigma attached to a diagnosis remains. One significant source of this modern stigma is perceived danger. Despite an increase in the

general public's acceptance and understanding of the neurobiological underpinnings of MHCs there is ample evidence of an increase in negative perceptions of the danger posed by individuals with psychiatric conditions which leads to public withdrawal, a moving away, of avoidance due to fear of those who receive a mental health diagnosis (Yanos, 2018). According to Hooley et al. (2021), some research shows that as many as 96% of schizophrenia patients have reported that stigma is a part of their everyday lives.

Stigma in the Workplace

The first and most significant impacts of my husband's diagnosis was the loss of his job. Despite being a well-respected, long-time member of his union who was said by the majority of his coworkers and employers to be exceptionally good at his job, he was immediately made redundant in the role he held at the time. He was ostracized by co-workers who, until that moment had been considered good family friends, people we socialized and even vacationed with. This had a significant negative impact on his recovery.

MHCs are considered to be a leading cause of disability throughout the world (Elraz, 2018). The economic impact of lost productivity and health care considerations due to MHCs are estimated to be a billion dollars a year in the United States alone (Follmer & Jones, 2018). Unfortunately, mental health stigma in the workplace plays a role in this. Employment rates among those with a diagnosed MHCs are extremely low. Numbers in the United Kingdom (UK) show only 20% of people with a MHC are employed. This is in stark contrast to the 75% of healthy adults in the UK who are employed while those with physical health challenges are employed at a rate of 65% (Wheat et al., 2010). This is despite extremely high reported rates of the desire of those with MHCs to obtain gainful employment, rates up to 90% according to research (Wheat et al., 2010). There continues to be explicit stigma and discrimination of those with a mental health diagnosis within the workplace (Elraz, 2018). According to Wheat et al., (2010) as many as a third of individuals with a mental health diagnosis claim they have been pushed to resign from a job or have been dismissed from their job due to their condition. Further, 40% of those with MHCs in the UK say they were not hired in the first place due to their history of treatment for a MHC (Wheat et al., 2010). Even more discouraging is that 60% of people with a diagnosed mental health condition reported they no longer felt comfortable applying for a job as they felt they would be treated in an unfair manner as a result of their diagnosis (Wheat et al., 2010).

In terms of those employed while dealing with a MHC, research shows lost productivity in the billions of days per year due to MHCs (Elraz, 2018). These missed workdays reduce overall workplace performance as well as contributing to further stigmatization in the form of isolation, discrimination, persecution, unemployment, or under-employment leading to low income and even social rejection in and out of the workplace (Elraz, 2018). These stigmatizing behaviours restrict “opportunities for promotion, [result in] micromanagement, over-attribution of mistakes to illness, malicious gossip and subtle forms of social exclusion” (Wheat et al., 2010, p. 83). According to Elraz (2018), this stigma may stem from MHCs continuing to be viewed through an historical context of prejudice. As shown by Elraz (2018), mental health stigma in the workplace also contributes to further impairment. This indicates some of the lost productivity and missed days result from the stigma associated with MHCs, not the conditions themselves. Not only are employees impacted by their condition, but they are also negatively impacted by stereotypes and myths regarding the abilities of those living with MHCs (Elraz, 2018). The universal stigma and extensive discrimination experienced by those with MHCs negatively impacts their ability to cope at work and even socialize (Elraz, 2018). As pointed out in Wheat et al. (2010), statistics support the findings of Elraz (2018) in that these discriminatory beliefs negatively impact the opportunities those with mental health diagnoses have to obtain opportunities in the workplace as well as leading to “feelings of [a] lack of competence at work” (p. 726).

The lack of professional recognition of those with mental health diagnoses leads many not to disclose their condition for out of fear that future career opportunities may be jeopardized by their condition (Elraz, 2018). Not only does this lead to individuals thinking they will be discriminated against but to actual discrimination in the workplace which leads to ongoing job insecurity and low status employment and well as poor integration into the work environment and ongoing marginalization (Elraz, 2018).

Stigma by Association

By far the most significant negative reaction my husband received regarding his diagnosis was from his mother. To this day she cannot accept that her child has a MHC. I believe the potential stigma of her association to an individual with a MHC, in this case the closest association possible for two people, that is having birthed and raised a child who is viewed as broken, is too much for her to contemplate. She both displayed stigmatizing behaviour directed at my husband and myself referring to her son as “worthless” and at the same time, feared being the victim of the stigma she

displayed. Once again, had he been diagnosed with cancer or some other disease with a simpler biological explanation, I believe my mother-in-law would have had a drastically different response. And research seems to support my feelings.

This type of stigma attached to family and friends of the patient, has been referred to as “curtesy or associative stigma” (Östman & Lars, 2002, p. 494). While there is less empirical research on stigma by association than other aspects of mental health, what research has been done highlights the negative impact on family in particular (Östman & Lars, 2002). In research by Östman and Lars (2002) they noted that a large percentage of relatives of those recently hospitalized for MHCs felt their social relationships had been negatively impacted by their association with the individuals with a MHC. There was also evidence that these family members considered this association to have a negative impact on their own mental health (Östman & Lars, 2002). Another interesting aspect of this study was their account of how the relatives of the family members felt inferior to staff and medical professionals. I believe this would be a stigmatizing experience for people. In fact, during my experiences with the mental health professionals who cared for my husband, this feeling was quite evident. Despite having a fairly good grasp of his condition and the medications the psychiatrist was prescribing, I can only describe the doctor’s attitude towards myself as condescending. As such, I can fully understand how this could be a very stigmatizing experience for family members. As elucidated in Östman and Lars (2002) this is a significant barrier to cooperation between the relatives of patients with MHCs and the professionals charged with their care.

This issue of poor cooperation was also strongly evident as I attempted to gather a comprehensive family history for doctors. Some family members, in particular my husband’s father’s family, were very forthcoming. Others, such as my mother-in-law, were not. She was extremely reticent to discuss her family and it was days before she was willing to acknowledge the addiction and MHCs her father experienced. Once again, I felt as though she was embarrassed to admit to this association due to the reflection on her. She feared being stigmatized by her association with her alcoholic father.

Like the historical Chinese belief that a mad relative would somehow taint the family, there is sufficient data which suggests family, spouses, and parents in particular, are often accused of causing MHCs in their loved one or somehow allowing the condition to continue (Sanden et al., 2015). This is confirmed in the way in which I have been treated in light of my husband’s

diagnosis. I have been directly accused of having driven my husband “crazy,” of somehow having caused his MHC or at least having played a role in the development of his condition. This response from people was not and still is not surprising to me.

I, too, had hoped for a different diagnosis. When I realized his behaviour was becoming extremely erratic and he started to imagine he was being followed by police, filmed, and his phone calls recorded by these faceless “others”, I was luckily able to have him admitted to hospital almost immediately. However, I did not expect the diagnosis he received, I had convinced myself there must be a simple biological cause, he had a brain tumour, that was the only logical thing. Unfortunately, a battery of tests failed to find a definitive physiological source for his inexplicable behaviour.

Of course, his diagnosis wasn't really a surprise. It explained so much of his past, of oddities throughout our nearly 20-year marriage as well as the extensive family lore of his “wild ways” as a younger man. However, I knew if he wasn't diagnosed with a tumour or a stroke, a seizure, anything else, if he was diagnosed with a significant MHC, that our lives would be forever changed. I knew I would be viewed differently, that I and our children would experience stigma by association. Sadly, my fears are realized on a regular basis as we navigate life with this condition.

Conclusion

Social and self-stigma plays a large roll in many people's reluctance to seek medical care for their symptoms (Hooley et al., 2021). There is evidence that this reluctance is particularly true for younger people as well as men and ethnic minorities. Stigma is a disproportionately greater deterrent to the seeking of treatment for two other groups: military personnel and (ironically) mental health professionals (Hooley et al., 2021). Despite the negative impacts of the stigma my husband faced, his diagnosis was also revelatory. Having a framework for understanding his sometimes-inexplicable behaviours provided somewhat of an explanation. As we move forward with improved diagnostics and treatment protocol, it is my hope people struggling with MHCs will have less reluctance in seeking help, that families will feel they can seek medical care for MHCs in the same way they seek treatments for loved ones with cancer.

Much of the current research and interventions address self-stigma and attempt to improve patients views of themselves (Yanos, 2018). Various treatment programs such as Narrative Enhancement and Cognitive Therapy, Ending Self-Stigma, Anti-Stigma Photovoice, and Coming

Out Proud show some success in helping patients reduce their self-stigmatizing language and thinking, but these programs do nothing to address community stigma (Yanos, 2018). As the causes of MHCs become clearer, and improvement to treatment becomes more available, it is my hope that the stigma associated with MHCs disappears. When people such as my husband continue to be successful and productive members of society, they pave a brighter path for those to come. He is once again proving his exemplary abilities at work. He is a loving and involved father and we all speak openly of his condition in the hope to reduce the stigma.

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