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Time to change course in stigma research?

As one of the world's longest running anti-stigma campaigns, *Time to Change* (UK), came to an end in March 2021, policy makers, campaigners and researchers will be looking to learn lessons to take forward into the next phase in the fight against stigma. This presents the perfect opportunity to revisit the stigma research landscape and ask important questions about what we have learned: from the very nature of stigma, to where we should go from here. This special issue highlights important articles from our collection in the field of stigma research, with particular emphasis on the experiences of stigma by mental health service-users, public understanding of mental distress, media portrayals, and the impact these have on stigma and stigma reduction efforts.

There are few people with experience of mental distress that would not be able to relate to what Goffman referred to as "the situation of the individual who is disqualified from full social acceptance"(Goffman, 1963). Public stigmatisation of mental distress results in social awkwardness, misunderstanding and exclusion. People in distress are morally judged and seen as *Other*. This is exemplified in research which suggests that the type of precipitating trauma can alter people's attitudes towards those experiencing PTSD symptoms (Krzemieniecki & Gabriel, 2019). Stigma causes the public to view some trauma survivors as more deserving of their symptoms than others.

Mental health stigma interacts with and reinforces other forms of stigma such as those based on race, ethnicity, religion, age, disability, gender and sexuality. The compounding impact of intersectional stigma can be seen in race-based bias in the diagnosis of schizophrenia which has led to disproportionately high rates of diagnosis and treatment of schizophrenia in African American people relative to white people (Neighbors, Trierweiler, Ford, & Muroff, 2003;

Strakowski et al., 2003; Sylvia Atdjian & William A. Vega, 2005). As a result of multiple layers of stigma, African Americans living with mental distress are often viewed as dangerous and unpredictable and receive different treatment by healthcare professionals, the police and members of the public.

An additional powerful impact is self-stigmatisation: the endorsement of negative public stereotypes about one's own experiences and the resulting behaviour changes and discrimination towards the self (Corrigan & Watson, 2002). The shame induced by stigma can leave a mark, leaving one feeling "inferior" or "immoral" and erode sense of self (Schwartz, 1956). Self-stigma has been associated with a number of negative outcomes, including increased depression, social avoidance, decreased self-esteem, worsening psychological distress and decreased help seeking (Drapalski et al., 2013).

Critically, stigmatising attitudes become detrimental to those affected by mental distress when they are enacted by individuals and institutions as discrimination. The behaviour of healthcare professionals, and public willingness for social connection with people experiencing mental illness are both negatively impacted by stigma (Knaak, Mantler, & Szeto, 2017; Sickel, Seacat, & Nabors, 2019). The implications of discrimination can be profound and include negative impacts on physical health, and other aspects which define quality of life, such as job opportunities and safe housing (Corrigan, Druss, & Perlick, 2014; Sharac, McCrone, Clement, & Thornicroft, 2010; Sickel et al., 2019).

As a result of the far-reaching negative impacts of mental health stigma, stigma reduction has formed a major area of research and public health agenda in the last twenty years, backed by impressive financial commitments from national governments and non-governmental organisations. Examples of national anti-stigma campaigns include *beyondblue* and *SANE* in Australia, *Opening Minds* in Canada, and the UK's *Time to Change* campaign - with extensions to Ghana, Nigeria, Kenya, Uganda and India through the *Global* program (*beyondblue*, 2014; Henderson & Thornicroft, 2009; SANE, 2021; Stuart et al., 2014). The approaches have been focused on improving public attitudes and behaviours through increasing education and social contact, challenging stigmatising media coverage, empowering people with lived experience of mental distress and promoting help-seeking.

An early review of large-scale anti-stigma campaigns showed that public education and contact with people experiencing mental distress had small positive effects on reducing stigma in programs across fourteen countries (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). Evaluation of the impact of *Time to Change* has shown an increase in mental health knowledge in around ten percent of people, a moderate positive effect on attitudes in around 13% of people and a small decrease in the level of desire for social distancing from mental distressed people in around 12% of people from 2009-2019 (Henderson, Potts, & Robinson, 2019). These positive changes support a small effectiveness of the campaigns though it is not possible to confirm direct causation.

Concurrent research relating to specific goals of the campaigns has been carried out, for example improving sensitive media coverage of mental health. Two articles in this special edition looked at media coverage of mental health in the period when anti-stigma campaigns have been prominent. Bowen and Lovell (2019) found that there was a significant reduction in the proportion of tweets on mental health from UK national press that were characterised as Bad News between 2014 and 2017. They also found that tweets characterised as *Understanding* significantly increased. Bowen, Lovell, and Waller (2020) analysed tweets about anorexia nervosa from the UK national press between 2009 and 2019. The authors concluded that overall, the views expressed were consistent with informed opinion, sympathetic towards people with experience of anorexia and advocated for improved service provision. This evidence is indicative of a trend in stigma reduction in the public realm, and this trend may be associated with the substantial anti-stigma campaigns.

On the contrary, the work by Bowen and colleagues also suggests that increasing knowledge and understanding of mental distress does not necessarily lead to a holistic and meaningful reduction in stigmatisation (2019; 2020). The authors found evidence of the continued presence of *Bad News* and sensationalist imagery used by the press in relation to mental distress during the years that *Time to Change* was in progress. This suggests that whilst the media may be increasingly willing to show sympathy for people experiencing mental distress, they have failed to move away from negative stereotypes which sustain othering. This notion is echoed in another study presented in this edition, which found that although knowledge of schizophrenia increased in a population sample between 2005 and 2017, perceptions of dangerousness and unpredictability did not (Gilmore & Hughes, 2019). This raises concerns about whether current anti-stigma efforts will authentically change the treatment of people who experience mental distress and how enduring this change will be.

So how and why, even as education and awareness of mental distress increases on a national level, does the public sustain practices which represent individuals experiencing mental distress as *Other*?

Evidence presented in this special edition, suggests that we still have far to go in developing a more nuanced understanding of how the public experience and understand mental distress

(Clay, Eaton, Gronholm, Semrau, & Votruba, 2020; DeLuca, Hwang, Stepinski, & Yanos, 2020; Green, Jones, Lyerla, Dyar, & Skidmore, 2020; Lyons, Evison, Berrios, Castro, & Brooks, 2020; Vovou, Hull, & Petrides, 2020). The campaigns of 2000-2020 have been criticised for largely promoting a biomedical explanation of mental distress based on the medicalisation of human emotions and diagnostic labelling (Walsh & Foster, 2021). Some have argued that emphasis on such models is divisive, perpetuating an "us" and "them" narrative which does little to combat stigma (Sweeney & Clement, 2014). This is supported by evidence that continuum-based explanations of mental health conditions are associated with more positive public responses and less desire for social distance (Schomerus, Matschinger, & Angermeyer, 2013; Thibodeau, 2020).

To challenge the *Othering* of individuals affected by mental distress, people with lived experience have increasingly called for anti-stigma approaches which are informed by an understanding of mental distress as a response to social and economic exclusion, violence and human suffering (Sweeney & Taggart, 2018). This is supported by evidence of increased prevalence of mental distress and serious mental health conditions in minoritized groups (Plöderl & Tremblay, 2015; Samaan, 2000). From this perspective, mental distress can be understood as a phenomenon with complex psycho-social, medical, and political dimensions.

Reframing mental distress as political encourages us to ask critical questions about the relationship between power, mental health, stigma, and discrimination. For example: whose knowledge and understanding of mental distress is being taught in stigma reduction efforts? One provocative argument for why stigma is sustained, despite large-scale, national campaigns and research efforts, is because the operationalisation of stigma helps to produce and maintain social inequality for the benefit of the privileged (Tyler & Slater, 2018). Stigma structures and amplifies the intersectional disempowerment of certain groups of people and the pathologisation of our emotions and trauma. Stigma can be used by those in positions of power to justify the policies which predispose, precipitate, and perpetuate mental distress.

In order to address this power imbalance, campaigns should be led by and for people with lived experience of mental distress. They should be underscored by human rights and community-based approaches and informed by survivor research (National Survivor User Network, 2019; Wells, Hancock, & Honey, 2020). Researchers should be actively and publicly anti-racist and anti-discriminatory. This should be made clear through the use of sensitive and inclusive language, the equitable treatment of colleagues and junior researchers, and the co-production of research with people who have been affected by mental distress.

To promote help-seeking and anti-discriminatory care, services should be transformed through embedding trauma-informed approaches at every level and addressing the power imbalances between providers and consumers to create respectful, restorative practice (Sweeney, Filson, Kennedy, Collinson, & Gillard, 2018). Survivor led models of conceptualising madness and distress and subsequent support models- such as the framework developed by Intentional Peer Support for mutual, cocreated mental health support- should inform service transformation ("Intentional Peer Support," 2021).

Interpersonal approaches to reduce stigma, through education of the public and increasing contact, are making progress but the extent and longevity of their impact is yet to be fully understood. To effectively confront stigma, we must change the course of stigma research by viewing it not as an individualistic exchange caused by insufficient exposure or understanding of mental health. We must pay attention to how stigma is woven into the fabric of our social and political systems to engender the exclusion, exploitation, and control of others (Tyler & Slater, 2018). Confrontation of the systems which are upheld by stigma, and utilised by the state, the media and those in positions of power in our society and communities is essential to reduce stigma and fight discrimination. This can only happen with the deliberate and committed empowerment of people who have historically be stigmatised and excluded from service development and research.

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