# 'People with Problems, Not Patients with Illnesses': Using Psychosocial Frameworks to Reduce the Stigma of Psychosis

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#### **ABSTRACT**

**Background:** Stigma and discrimination are major difficulties for people with psychosis. However, despite the dominance of biomedical ideology in public education and de-stigmatization efforts, there is substantial evidence that campaigns based on the "medical model" (such as the "mental illness is an illness like any other" approach) are not only ineffective, but can actually compound the problem. This paper considers the alternative role of psychosocial explanatory frameworks in promoting more tolerant and enlightened approaches to, and attitudes about, psychosis.

**Data:** A summary of theoretical and empirical research on the effectiveness of mental health anti-stigma campaigns is presented.

Conclusions: There is a reasonably substantial evidencebase supporting the hypothesis that anti-stigma campaigns which frame psychosis as a meaningful response to adversity are effective. They are a more promising approach to "humanizing" people with complex mental health problems than strategies based on models of disease and disability.

Prejudice and social rejection are a source of significant distress for individuals with a diagnosis of psychosis/schizophrenia, and can be experienced by many as more debilitating and persistent than the mental health problem

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itself (1). Negative attitudes frequently incorporate the "toxic triad" of perceived dangerousness, unpredictability and lack of recovery potential (2), and have been observed among the general public (3), in media representations (4), as well as in both psychiatric staff (5) and other healthcare professionals (6). In turn the consequences of stigma are severe and widespread, including social marginalization, discrimination in employment, education and housing (2, 7-9), as well as feelings of internalized stigma (10), diminished ambition and quality of life (11), hopelessness (12), and impairment of recovery prospects (13).

Significant resources have been expended in trying to reduce the burden of stigma, most notably through public health initiatives designed to improve "mental health literacy" (14). Although strategies vary, a central tenet of many such programs is educating the public to understand mental distress as a form of biogenetically based illness or disease, in effect that "mental illness is an illness like any other." A major rationale behind this approach is that emphasizing the biogenetic nature of psychosis (and other mental health difficulties) might absolve individuals of blame and responsibility, in turn leading to less condemnation and more positive attitudes. However despite their dominance – and the undoubted good intentions that drive their application – there is substantial evidence that these approaches are not only ineffective, but in some cases can actually compound the problem. In considering the research relationship between biogenetic causal beliefs and negative attitudes, this paper will explore the argument that framing individuals as "people with problems" as opposed to "patients with illnesses" (15) is a more promising and robustly evidencebased strategy for reducing stigma and prejudice.

# ANTI-STIGMA CAMPAIGNS: PSYCHOSOCIAL VS. BIOGENETIC EXPLANATORY FRAMEWORKS

In emphasizing the role of psychosocial causal models for combating stigma, it is important to first highlight the considerable evidence base for the impact of adversity in the etiology of psychosis. In the past two decades a rapidly accruing literature, derived from a variety of research designs and assessment methods, has repeatedly demonstrated that a range of negative life events (particularly, but not exclusively, childhood abuse) are powerfully associated with both psychotic symptoms and a diagnosis of schizophrenia; this relationship is not only dose-dependent, but remains significant when controlling for a range of clinical and demographic confounders (for reviews, see 16-19).

This relatively recent research confirms the evidence, spanning over 60 years, that the general public emphasizes and endorses the impact of psychosocial factors (e.g., abuse, poverty, stress) on mental health over that of biology or genetics (for review, see 20). In turn, repeated research shows that individuals with a diagnosis of psychosis/ schizophrenia consistently cite psychosocial factors as a more significant cause of their distress than biological ones (20-23) with one study reporting that 297 of 306 "typical schizophrenics" (97%) rejected the idea that they had an illness (24). Nevertheless, a recurring emphasis of "mental health literacy" (often with the financial backing of the pharmaceutical industry, 25) is essentially to persuade the public that they are mistaken (26). In this regard, a series of literature reviews (2, 3, 26-28) and meta-analyses (3, 29, 30) have repeatedly concluded that anti-stigma campaigns based on the "mental illness is an illness like any other" approach are consistently failing to acknowledge what research actually shows about what is effective, and ineffective, in reducing mental health stigma.

#### **CORRELATIONAL RESEARCH**

Typical methodology for assessing associations between explanatory models and stigma involve correlating respondents' causal beliefs about mental health problems (i.e., psychosocial or biogenetic) with attitude measures (e.g., fear, perceived dangerousness and unpredictability) and/or assessing intentions for social proximity (e.g., willingness to socialize, live nearby, or work with). Overwhelmingly, evidence demonstrates that biogenetic beliefs are associated with worse outcomes. In this regard Read et al. (26) have summarized findings from 22 such studies,

published between 1975 and 2011 and derived from 14 different countries, and found that of 24 statistically significant findings pertaining to biogenetic explanatory frameworks, 96% (n=23) were associated with negative attitudes. In contrast, of the 13 significant results relating to psychosocial frameworks 92% (n=12) were associated with positive attitudes. Furthermore, while much research was cross-sectional, the association appears to be sustained longitudinally. For example, trend analyses using population surveys in Germany from 1990-2011 (31) and the U.S. from 1996-2006 (32) found that increased "mental health literacy" was associated with an increased desire for social distance from people diagnosed with schizophrenia (31); while public belief in biogenetic models increased endorsement for psychiatric treatments, they had no positive effects on stigma and were associated with increased rates of social rejection (32).

More recent research also supports this pattern. For example, a German survey of 3,642 members of the general public found that neurobiological explanations ("chemical imbalance of the brain," "brain disease") were associated with stronger desire for social distance regarding both schizophrenia and depression. Although "heredity" was not correlated with social distance, all biogenetic causal beliefs were associated with more fearful emotional reactions; findings that remained significant when controlling for socio-demographic variables among respondents (33). Similar results have been reported by Angermeyer et al. (34), who surveyed German householders via telephone with case vignettes representing both depression and schizophrenia. Regardless of whether or not a psychiatric diagnosis was mentioned (as opposed to simply describing symptoms), assigning biological or genetic causes was not associated with a reduced desire for social distance, with a "brain disease" framework further associated with a greater desire for social distance in schizophrenia (although not depression).

In turn, a meta-analysis (29) of 25 studies (Ns = 4,278–23,816) reviewing the relationship between biogenetic explanations for mental health problems and three key elements of stigma (blame, perceptions of dangerousness, and social distance) found that while biogenetic explanations only accounted for a small proportion of individual variation in stigma (and varied in subgroup analyses according to the type of mental disorder examined, the nature of the sample, and the type of explanation employed), biogenetic causal models were negatively associated with blame (r = -.19), but positively associated with perceived dangerousness (r = .09) and desire

for social distance (r = .05), particularly in the case of schizophrenia.

#### **EXPERIMENTAL RESEARCH**

In contrast to associational research experimental studies involve direct manipulations, typically showing participants a video or written case vignette of the same individual but with alternative causal accounts of his or her experiences. Read et al. (26) present data from 17 such studies, published in six different countries between 1963 and 2011, and likewise report a substantial benefit of psychosocial approaches. Specifically, out of 13 statistically significant findings, a psychosocial explanatory model improved attitudes in all cases. Of the seven significant findings relating to biogenetic frameworks, attitudes were improved in only 29% of cases (n=2) and actively worsened in 71% (n=5). In terms of actual behavioral change, one study (35) additionally found that participants in a learning task exhibited harsher responses (administering electric shocks) if they were told their counterpart's mental health difficulties were related to disease as opposed to childhood adversity.

More recent experimental research also supports this view, including the finding that accompanying case vignettes with biological explanations evoke significantly less empathy among mental health professionals compared to psychosocial information (36) and that educational interventions which emphasize psychosocial models of schizophrenia are effective for reducing perceptions of unpredictability/dangerous, and increased belief in recovery among medical and psychology students (37, 38). In a latent class analysis of 366 students responding to case vignettes, Mannarini and Boffo (39) further report that people diagnosed with schizophrenia were classed as being of low danger, but also highly socially rejected, with biogenetic etiology and treatments largely endorsed. In contrast, bulimia, anxiety and depression were evaluated "less prejudicially," with low perceived dangerousness, low social distance, and mostly attributed to a psychosocial or bio-psychosocial etiology, with psychological treatments endorsed.

In turn, a meta-analytic review of 28 experimental studies (Ns = 1207-3469) has assessed the impact of biogenetic causal models on blame, perceived dangerousness, social distance, and prognostic pessimism on a range of mental health conditions (30). Similar to other reported findings, biogenetic frameworks were found to alleviate blame (Hedges g = -.324), but increase pessimism

(g = .263) and perceived dangerousness (g = .198), although did not typically influence social distance. While acknowledging a possible effect of publication bias, the authors conclude that "Explanations that invoke biogenetic factors may reduce blame but they may have unfortunate side-effects, and they should not be promoted at the expense of psychosocial explanations, which appear to have more optimistic implications." (30, p.790).

## THE NEGATIVE IMPACT OF BIOGENETIC MODELS

Despite a striking lack of success in reducing stigma, there can be no doubt that "mental health literacy" campaigns are well-intentioned, and based on a seemingly sound premise: that emphasizing the sickness and disability of psychiatric patients should garner tolerance and compassion. Why then does the evidence indicate not only failure but, in some instances, an exacerbation of the problem?

The Canadian Health Services Research Foundation (40) has considered this very question, and identified three key reasons as to why biogenetic explanatory frameworks appear to compound stigma rather than alleviate it. Firstly, they suggest that while portraying patients as sufferers of a biogenetic condition might reduce the blaming impulse (that is, it is not an individual's fault that s/he is unwell), the message that the condition is biologically determined promotes the false belief that behavior is beyond conscious control. Thus the public are more likely to perceive patients as impulsive, unpredictable, and ultimately dangerous. Secondly, biogenetic models foster as "us and them" mentality, which in turn creates the desire for social distance. As Longden, Read and Dillon describe it: "emphasizing a categorically different group characterized by fundamental biological/genetic abnormalities drives the reciprocal mechanisms of fear, avoidance, and scapegoating which, in turn, exaggerates the differences between 'the mad' and 'the sane' and denies the dimensionality of emotional distress" (41, in press). Thirdly, because the public often perceives mental health conditions as difficult to treat, a disease framework augments the idea that psychiatric patients have poor recovery prospects and are likely to experience difficulties that are chronic and severe. Taken together, these lines of reasoning clearly demonstrate why destigmatization campaigns based on biomedical frameworks are unsuccessful because they foster an image of a fundamentally different group, whose behavior is potentially unpredictable and high-risk, yet who are unable to actively alleviate their condition and for whom the capacity for full recovery is negligible. By taking this argument to its logical conclusion, the Foundation thus notes that "Presenting mental illness in the context of psychological and social stressors normalizes symptoms, creating a healthier public perception" (40, p.3).

Research from the field of social psychology provides further understanding of why biomedical models fail to reduce stigma, specifically in reference to the concept of "essentialism." As a construct, essentialism has a long provenance in both the physical and social sciences, and refers to the tendency to identify groups according to their perceived attributes, or "essence." A common and benign example is taxonomy, wherein animals are grouped according to biological traits. However, when applied to human beings, essentialism can be both controversial (e.g., the contention among gender theorists as to whether men and women are fundamentally different) and destructive (e.g., categorizing individuals according to race). In effect, this form of thinking "reduces a complex being to 'one essential characteristic" (42, p. 201), and it is known that individuals who hold essentialist biases about various aspects of human diversity (e.g., ethnicity, gender, sexual orientation) are more likely to demonstrate prejudicial perspectives (43). In turn this is more likely to occur when the "essence" in question is perceived in terms of biological markers because of the ways these highlight the supposed differences between the discriminator and the stigmatized group. In a classic paper on the subject, Dar-Nimrod and Heine (44) summarize these essentialist biases in the following way: "Learning about genetic attributions for various human conditions leads to a particular set of thoughts regarding those conditions: they are more likely to be perceived as (a) immutable and determined, (b) having a specific etiology, (c) homogeneous and discrete, and (d) natural, which can lead to the naturalistic fallacy" (p. 800).

As discussed previously, disease models create ideal conditions for fostering essentialist views of mental distress by reducing a complex experience to a biogenetic "essence." Haslam (45) has drawn on Dar-Nimrod and Heine's work to provide a specific analysis of how essentialist frameworks can create stigmatizing attitudes towards mental health problems (see also 46-48). In addition to the issues of perceived uncontrollability and permanence outlined by the CHSRF, Haslam also emphasizes the destructive issue of stereotyping, in that essentialist thinking around mental health makes individuals more likely to accept simplistic, pejorative images of psychiatric patients, as well as what Benning et al. describe as "an

exaggerated attribution of 'other-ness'...further reinforced by the use of...dichotomous constructs such as...sane/insane and normal/pathological" (49, p. 89). In contrast, individuals who reject biogenetic dichotomies in favor of continuity between "schizophrenia" and "normality" exhibit consistently lower levels of stigma (50). As a somber conclusion, Haslam (51) further notes that an inevitable result of essentialist thinking around psychosis is dehumanization, wherein if "essentialist thinking leads us to view those with mental health problems as categorically different, uncontrollable, and untamed, it should be no surprise that they will also be seen as less than fully human" (26, p. 70; see also 52).

Finally, recent work by Kvaale and Haslam (53) has further explicated ways in which the ambiguous nature of biogenetic models (i.e., reducing blame while heightening perceived dangerousness, uncontrollability and prognostic pessimism) might increase stigma according to an individual's social motivations. Specifically, their studies found that the desire to compete for group dominance (Social Dominance Orientation: SDO) and preserve security and social cohesion (Right Wing Authoritarianism: RWA) were associated with stigmatizing attitudes toward depression and schizophrenia (n=177). In turn, SDO and RWA predicted how a second sample (n=93) responded to explanations for schizophrenia, with biogenetic explanatory models predicting high stigma in high-RWA individuals and low stigma in the low-RWA group.

### ALTERNATIVE APPROACHES: SHARING STORIES TO REDUCE STIGMA

Biomedically-framed campaigns may reduce the blaming impulse towards psychiatric patients, as well as enhance assurance in psychiatric treatments and clinicians, yet they have also had the profoundly unfortunate result of heightening rejection and prejudice towards the very individuals such services are designed to support (32). Several decades of research evidence now clearly attest to the urgent need to reform stigma reduction campaigns in ways that can genuinely promote acceptance, compassion, and community inclusion. Framing mental distress as an understandable response to adversity is clearly one way of accomplishing this, but what other elements might be considered in devising such approaches?

In this regard continuum models have an obvious role to play, not least because their emphasis on de-pathologizing and continuity erodes the "us and them" mentality that perpetuates prejudice. Just as cognitive behavioral ther-

apy for psychosis (CBTp) includes normalization as a key therapeutic component (54), educating the public about the continuum between "mentally ill" and "mentally well" - deconstructing what Benning et al. (49, p.189) describe as the "myth of difference" - is a promising approach for combating stereotypes and discrimination (50). In turn, another feature of normalizing mental distress may include emphasizing specific experiences in anti-stigma campaigns, as opposed to generic psychiatric diagnoses. Kingston et al.'s (55) recent study on the impact of different causal explanations for voice-hearing on the public's attributions and behavioral intention provides some support for this reasoning, in that they reported the unusual finding that perceptions of dangerousness were not influenced by biological causal explanations. The authors propose that their use of "symptom level" descriptions (i.e., voice-hearing) in the case vignettes rather than diagnoses may have influenced this, and it is certainly known that labeling experiences as "schizophrenia" (as opposed to not apportioning a diagnosis) heightens negative beliefs and attitudes (56), with the schizophrenia label likewise linked to increased self-stigma, perceived stigma, and experienced stigma (10).

In addition to challenging stigma through education, it is also important to create positive attitudes and increase "ascribed humanity" (52, p.1) towards psychiatric service-users. Heightening social contact is one means of achieving this, including initiatives that give individuals with lived experience of mental health problems the opportunity to share stories of hope and recovery, as well provide testimony on how prejudice and discrimination have affected them (57). However, a review paper by Rüsch et al. (58) on strategies to reduce mental health stigma has also emphasized that interpersonal contact should ideally occur within particular parameters to be most advantageous, including institutional support for the initiative and equitable, cooperative interactions between participants. In addition to experimental work (see 58-60), naturalistic studies (e.g., the Time to Change initiative, "Get Moving!" events and Living Libraries: see 61) have also shown the value of facilitating social contact on a population scale. In turn, this also includes the demonstrated benefits of involving psychiatric service-users in designing and delivering training curriculums for students of psychology and medicine (37, 61, 62). In this regard, a recent quasi-randomized controlled study (38) has reported that an educational intervention combining psychosocial scientific research with testimony from individuals diagnosed with schizophrenia was associated with greater prognostic optimism, greater endorsement for psychosocial causes and treatments for psychosis, and

lower perceptions of unpredictability and dangerousness among 76 psychology students. In contrast, the 112 students who did not receive the intervention showed no significant changes in beliefs or prejudicial attitudes.

Finally, as noted by Read et al. (26), mental health antistigma efforts emphasize causal models in a way that is not apparent in other initiatives (e.g., in combating discrimination against wheelchair users the origins of the disability is immaterial). Instead, prominence is placed on citizenship, inclusion, and the right to a fulfilling and rewarding life of the individual's choosing irrespective of causal frameworks. In this regard, the work of the Terence Higgins Trust (and other HIV and AIDS foundations) provides an encouraging example of how it is possible to improve the public's "literacy" and awareness about a condition while also successfully challenging prejudice and stigma (63). As opposed to purely educating the general public about the causes of mental health difficulties, promising adjunct strategies for stigma reduction can therefore include: increasing empathy and tolerance for perceived difference (64); challenging stereotypes and protesting against damaging media representations (57, 58); tailoring interventions for different groups (e.g., adults and young people [65]; policy makers and professional and social bodies [66]); using legislation to target prejudicial practices and structural/institutional discrimination (67), and using affirmative action to support the positive participation of individuals with mental health problems at all levels of society (66).

#### **CONCLUSIONS**

Prejudice and discrimination are a major challenge and recovery impediment for individuals with psychosis. While anti-stigma initiatives based on the "mental illness is an illness like any other" approach are well-intentioned, there is substantial evidence that they are not only ineffective but can actually increase attributions of dangerousness and desire for social distance. An important aim for future research and policy is finding ways to reduce the "us and them" mentality that perpetuates stigma, including the rejection of essentialist frameworks that reduce complex experiences like psychosis to a series of biological markers - and in doing so encourage exaggerated beliefs about abnormality and difference. There is evidence that locating mental distress as an understandable response to life adversity is one means of achieving this, although it is also important to locate such efforts within the wider socio-political goal of challenging systematic forms of intolerance and prejudice towards a minority experience.

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