

Lessons learned from unintended consequences about erasing the stigma of mental illness

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Advocates and scientists have partnered to develop and evaluate programs meant to erase the egregious effects of the different forms of stigma. Enough evidence has been collected to yield lessons about approaches to stigma change. Some of the most insightful of these lessons emerge from unintended consequences of good intentioned approaches, and are the focus of this paper. They include the limited benefits of education especially when compared to contact, beating stigma is more than changing words, beware pity as a message, understand the competing agendas of stigma change, replace ideas of normalcy with solidarity, and avoid framing self-stigma as the problem of people with mental illness and not of society. The paper ends with consideration of the back seat role that psychiatrists and other mental health providers should have in stigma change.

Key words: Stigma, mental illness, unintended consequences, education, contact, public stigma, self-stigma, label avoidance, services agenda, rights agenda, solidarity

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Eliminating stigma's egregious effects on people labeled "mentally ill" has become a major public health priority across the world, with many countries combating stigma over the past ten years via nationwide campaigns.

During this time, research on stigma and stigma change has grown exponentially, from just six papers in the four year period in which A. Farina instituted the first empirical work on mental illness stigma circa 1970, to 22 papers in the time B. Link began his important program of research in the early 1980s, to 1,008 papers since 2010.

The interface of national campaign evaluations with empirical research found in the professional journals has led to several lessons that might be heeded in moving forward to erase stigma. Some of these are discussed here. The paper begins with brief answers to "What is stigma?", focusing especially on its harmful impact. Given the breadth and complexity of the stigma experience, this discussion is mostly limited to the egregious effects of public stigma on the person with mental illness. The paper then focuses on ways to eliminate stigma, largely focusing on negative lessons – good intentioned approaches that nevertheless yield little or even harmful impact.

Why the focus on unintended consequences? Stigma is largely an issue of social injustice and as such attracts people with progressive agenda. Progressive philosophy in the U.S., for example, called for using science and social forces to erase the ills that lead to poverty and discrimination¹. Progressives rally energetically against egregious social phenomena, but often do so without consideration of effective approaches, sometimes worsening the status quo. For example, B. Clinton promoted "Don't ask; don't tell" in the 1990s as a way to decrease homophobia in the American military. Unfortunately, this promoted closetedness and secrecy in the gay community. Avoiding errors is as important an effort in tackling stigma as erasing discrimination, hence the need to learn from good intentioned strategies gone awry. Reviewing unintended consequences makes us better able to recognize potentially beneficial approaches.

WHAT IS STIGMA?

Several models have emerged to explain stigma, including Link and Phelan's approach² that unpacks the complicated elements of the phenomenon, and Pescosolido et al's framework³ integrating normative influences on stigma. I expand in Table 1 on a two dimensional matrix representing cognitive constructs that emerge from social psychology and a typology of impact.

Social cognitive models have outlined various constructs that describe the generic stigma experience across all disrespected groups (racism, sexism and homophobia) and include stereotypes, prejudice and discrimination⁴. Stereotypes are knowledge structures that evolve as part of "normal" development in a culture. They are often framed as seemingly fact-based beliefs with a negative evaluative component. Stereotypes become prejudice when people agree with the belief followed by negative emotions and evaluations of the group involved^{5,6}. Discrimination is the behavioral result of prejudice, typically punitive in form and experienced as taking away a rightful opportunity or reacting to the group aversively.

Research has identified a variety of prejudices and discriminatory behaviors reflecting the stigma of mental illness. Several of these are listed in Table 1, including those most commonly reported in the research literature^{7–10}. Perhaps most damning is that of dangerousness: that "those people" are potentially violent felons. Dangerousness is highly associated with fear, which leads to avoidance and withdrawal, the discriminatory result.

The three types of stigma summarized in Table 1 are public stigma, self-stigma and label avoidance.

Public stigma occurs when the general population endorses the stereotypes of mental illness and acts upon them in a discriminatory manner. The most troubling form of discrimination is avoidance and withdrawal. In order to escape the risks of associating with people with mental illness, members of the general public will seek to avoid them. Avoidance is especially hurtful when acted on by employers who do not hire people with mental illness and landlords who do not rent to them.

Table 1 A two dimensional matrix for understanding stigma: types by social cognitive constructs

TYPOLOGY FOR HEALTH IMPACT				
CONSTRUCTS		PUBLIC STIGMA	SELF-STIGMA	LABEL AVOIDANCE
COGNITIVE	PREJUDICE (stereotypes)	"He is dangerous"	"I am unreliable"	Diagnosis of mental illness means "crazy"
BEHAVIORAL	DISCRIMINATION	Employer refuses to hire person with mental illness	Person with mental illness does not take on new tasks	Individual refrains from going to the clinic to seek help

Self-stigma occurs when people internalize prejudice and discriminate against themselves. Self-stigma has been divided into progressive stages known as the three As: aware, agree and apply^{11,12}. Is the individual with mental illness *aware* of the stereotypes? For example, does the person know the stereotype that individuals with mental illnesses are childlike, incompetent, and so will not meet the demands of their job? Does the person *agree* with the stereotype? ("Yes, people with mental illness are incompetent and not capable of keeping up with the demands of competitive employment"). Do they then *apply* the stigma to themselves? ("I have a mental illness so I must be incompetent"). Applying or internalizing stereotypes has two harmful effects. Cognitively and emotionally, internalizing stigma can hurt self-esteem ("I am not a good employee; I cannot keep up with the demands of my job because I have a mental illness") and lessen self-efficacy ("I can't keep up with my job because I am an incompetent person with mental illness"). Behaviorally, the three As lead to the "why try" effect^{13,14}: "Why should I try to get a promotion? I am not worthy of it"; "Why try to seek out a job? I am unable to be successful".

Label avoidance refers to a third type of stigma; namely, stigma undermines service use for individuals in need of psychiatric care. One way in which people are publicly labeled is by associating with a mental health program: "Hey, that's Karen. She is coming out of that psychiatrist's office. She must be nuts!". To avoid labeling, some people refrain from seeking services that would be helpful, or do not continue to use services once initiated.

WHAT LESSONS HAVE BEEN LEARNED TO CRAFT ANTI-STIGMA EFFORTS?

Although explaining stigma and its negative impact is a research priority, the ethical imperative driving this work

comes from advocacy efforts meant to erase it. Just as the most effective clinical interventions arise in a partnership of researchers and line-level practitioners, so effective research programs on stigma change rely on partnership between advocates with lived experience and social scientists.

Based on a review of the social psychology literature, approaches to changing public stigma have been divided into protest, education and contact strategies¹⁵. Protest relies on an appeal to a moral authority (shame on us for disrespecting people with mental illness), leading to a call for suppressing these thoughts. Education seeks to decrease stigmatizing myths of mental illness by contrasting them with facts. Contact tries to erase the prejudice and discrimination of mental illness through interactions between the "public" and people in recovery. Most of the research on public stigma change has examined education and contact; hence, these two approaches are the focus of the remainder of the paper.

Education or contact

Education has a seductive appeal to many countries: address social ills by teaching people about them. And in fact, efforts that promote mental health literacy may help people to better consume services, because they better understand how psychiatric disorders can challenge life goals and how these disorders can be overcome¹⁶.

Research suggests, however, that education has little impact on the prejudice and discrimination that limit a person's rightful opportunities. Schomerus et al¹⁷ reviewed sixteen population studies that tracked evolution in knowledge about mental illness and corresponding change in stigma from 1990 to 2006. Results showed significant increase in population knowledge

that illnesses such as depression and schizophrenia are genetic in origin and hence brain disorders. For example, a median 75% of respondents in 2006 agreed that schizophrenia is a brain disorder compared to about 55% in 1990. Despite this change, no improvement in the stigma of depression was observed, and the stigma of schizophrenia actually worsened. Stigma was defined here as accepting a person labeled schizophrenic as a neighbor or coworker. Acceptance of coworkers labeled with schizophrenia decreased from 50% to about 30% during the 16-year span of data. Despite increases in knowledge, stigma has not changed, or it has actually gotten worse.

Unintended effects of education emerge when considering programs that frame “mental illness as a brain disorder”. Summaries by Read and colleagues show that endorsement of this view is highly associated with beliefs that people with mental illness are dangerous and incompetent^{18,19}. A study by Phelan et al²⁰ demonstrated the specific effects of teaching the public about genetic models of mental illness. The good news was, as expected, that this kind of education decreased blame: “People do not choose to have a mental illness; it is biological in origin”. However, genetic models also lead the public into believing that people will not recover; that the mental illness is “hard wired”. Poor prognoses result which are more likely to predict whether an employer will hire people with mental illness or a landlord will rent to them.

Several research studies have directly contrasted effects of education and contact. Results of a meta-analysis with thirteen randomized controlled trials showed that contact, compared to education, yielded significantly greater change in attitudes and behavioral intentions from pre- to post-test. Moreover, follow-up effects were significantly greater for contact than education²¹. By the way, research from the meta-analysis also showed that *in vivo* contact had better impact than contact that occurs through some medium²¹. Specifically, face-to-face interactions with people with mental illness has greater impact than hearing their story through video.

Beating stigma is more than changing words

Stigma related to mental illness is often understood in terms of labeling; e.g., tagging people with the diagnosis of schizophrenia brings upon the negative impact of stigma. As a result, professionals and advocates have called for changing labels of mental illness in order to reduce its stigma²². This has been done for other disorders: dementia is now Alzheimer’s disease, mental retardation is intellectual disability, and manic-depressive illness is bipolar disorder.

Name changes for schizophrenia have been proposed by several East Asian professional associations, in part to highlight the optimism of recovery in prognosis. This is a relatively new endeavor, so research on its impact is still evolving, much of it from Japan, which changed the disrespectful name for schizophrenia to “integration disorder”. Research shows that psychiatrists and other mental health providers soon learned new labels²³. Awareness of the new diagnostic label was in-

versely associated with conscious and unconscious measures of social distance^{23,24}.

Still, even if renaming mental illness could show some stigma change, the effort fundamentally misunderstands the pernicious effects of prejudice and discrimination. Whether people with serious mental illness are labeled with schizophrenia, or a more benign and informed label like integration disorder, the person may still be marked as different. The harm of stigma arises from both the mark and the difference²⁵.

Racism did not disappear in America because the majority now call black people African Americans. Social scientists called putative changes like these “modern racism”, where obvious forms of discrimination may disappear – for example, media, politicians or marketing experts no longer refer to groups of color using egregious terms – but discrimination continues in subtle forms, e.g., opposing busing for elementary school students²⁶. Diagnosing people with integration disorder may not lessen the discrimination they experience from landlords, employers and legislators.

In addition, promoting diagnostic relabeling to erase stigma makes the anti-stigma agenda look easy. All we need to do is change the words. Unfortunately, believing stigma change is easy has its consequences. Funding bodies like the U.S. National Institute of Mental Health are modifying their priorities, and support for research in stigma has waxed and waned over the past decade. Some professional groups believe anti-stigma programs are no longer needed²⁷. Diagnostic relabeling encourages word police, prodding media and others to improve their language. Research shows, however, that protest efforts to stop inappropriate words do not diminish stigma, and sometimes even worsen it¹⁵.

Beware pity: it’s about parity

The symptoms and disabilities of mental illness, by their very definition, challenge happiness and hope. Reasonable reactions to mental illness include sadness and sympathy. Research suggests that educational programs focusing on biological causes may increase pity, or sympathy, for people with mental illness²⁸⁻³⁰.

Weiner³¹ argued that sympathetically viewing a person as victimized by various health conditions – including cancer, HIV/AIDS and heart disease – is associated with willingness to provide help to that person. Research specific to psychiatric illness has shown that members of the general public who pity individuals with mental illness are more willing to offer a helping hand to them³².

Hence, pity might be used as a way to promote legislative movement for greater resources for mental health programs. In fact, research showed a significant relationship between viewing people with mental illness pitifully and endorsing the allocation of more funds for mental health services³³. Further analyses showed, however, that it was greater resources for mandated treatment, and not rehabilitation services, that was associated with greater pity.

Pity may also produce negative effects, because of an over-reliance on or dramatization of what persons with illness and disability cannot do. Pity may create a different stigma, e.g., people with mental illness are incapable of making adult-level decisions²⁰. Viewing people with illness as pitiful has been associated with the benevolence stigma, i.e., because people with mental illness are unable to competently handle life's demands, they need a benevolent authority who can make decisions for them³⁴⁻³⁷.

Advocates and researchers have argued that a major problem with many health systems is disempowering practices that prevent people with disabilities from pursuing life goals³⁸⁻⁴⁰. Appeals to sympathy must be replaced by calls for empowerment and self-determination. All decisions about life goals and the interventions to achieve those goals must stay in the hands of the person with mental illness. This message rests on the knowledge that people with mental illness often fail because of community and systemic inequities. Anti-stigma advocates need to cultivate empathy that leads to parity, not to condensation and exaggeration of difference. Advocates clearly voice the goal: parity, not pity!

Competing goals in stigma change

The impact of public stigma, leading to prejudice and discrimination that undermine pursuit of life goals related to work, independent living and personal relationships, differs markedly from label avoidance, such that people do not seek out mental health services in order to avoid stigmatizing labels.

Targeting stigma to erase these different impacts may yield separate agenda: *the services agenda*, trying to remove stigma as a barrier to becoming engaged in evidence-based services, and *the rights agenda*, replacing discrimination that robs people of rightful opportunities with affirming attitudes and behaviors. Approaches to these agenda were developed and matured independently, leading to different purposes and processes.

The services agenda

Decreasing label avoidance in order to promote mental health service seeking has become a major public health endeavor⁴¹. The Australian program called *beyondblue* tackles label avoidance and care seeking. It is a social marketing campaign which includes public service announcements framing depression as a treatable disease. It has been active in Australia for almost 15 years, and shown to have penetrated the population well, with 60% of Australians being aware of the program⁴². Campaign awareness was associated with better recognition of mental illnesses and greater understanding of treatment benefits⁴³.

Mental Health First Aid is a mental health literacy program that also has sought to diminish label avoidance. It is an 8-hour course taught in a classroom setting that reviews basic information and skills, so that course participants can help others with mental health problems or crises. Outcome research on this program is promising: findings from a recent

meta-analysis show that people who complete first aid training are likely to have mastered information about mental illness and show diminished stigma⁴⁴. This kind of information should boost care seeking.

The rights agenda

Programs meant to erase public stigma are seeking to promote civil rights. Erasing discrimination is not enough; the population needs to replace prejudice with affirming attitudes and behaviors. Affirming attitudes promote recovery and pursuit of individual goals based on ideas of hope, empowerment and self-determination. Affirming behaviors are community actions that firm up recovery and self-determination. They include innovative ways to provide reasonable accommodations and meaningful supports.

Opening Minds is a nationwide effort in Canada that largely rests on contact-based interventions⁴⁵. It sought to build networks of practice, collections of small contact-based programs from across the country that were reimbursed for local anti-stigma efforts. Preliminary analyses of this six-year initiative seem to suggest that contact programs have positive effects on targeted groups of youth, health care providers, Canadians in the workplace, and the media.

What is the significance of different goals?

The two approaches to stigma change differ in fundamental purposes and processes. They differ in message. The services message seeks to destigmatize mental illnesses by framing them as treatable disorders. The rights message poses mental illness stigma in the same light as any civil right, calling for ending discrimination and promoting opportunities.

These messages lead to differences in expected benefits, which lead to differing research measures of their success. The services agenda is successful when evidence shows that people with mental illness are seeking out services more or becoming better engaged. The rights agenda is successful when, for example, there are more people with mental illness in the workforce receiving reasonable accommodations.

The different agendas may be driven by people with different roles in the mental health system. The services agenda is propelled by people who are confident that treatment helps: those who have benefited from interventions and their families. This approach is often supported by service providers and their professional organizations. The rights agenda is driven by those who have been victimized by discrimination, either directly or through the experiences of others.

Agendas may turn to different strategies to promote their goals. The services approach is dominated by health communication and public service campaigns meant to influence a broad population. The rights approach is more grassroots, using people with lived experiences and stories of recovery to challenge local examples of discrimination and promote community opportunities.

The different agendas may compete with each other. Summaries and evaluations of government programs with 5 to 10-year histories in the U.S., U.K., Canada and Australia show that they are limited by available funds. As a result, choices need to be made in budgets for social marketing campaigns to enhance service seeking versus those for grassroots efforts to promote rights. There is never sufficient money for all proposals, so benefits for one may limit the other.

The nature of the message: normalcy versus solidarity

Goffman⁴⁶ characterized stigma as “undesired differentness” that results from a mark distinguishing and discrediting an out-group from the majority. People with mental illness are different from the norm, and hence, somehow broken. One way to erase stigma has been to accentuate similarities between people with mental illness and the rest of the population through an appeal to normalcy. “Despite his schizophrenia, Harold is just like everyone else”. In this light, Goffman believed stigmatized people can be active agents in diminishing difference through impression management, the strategic effort to minimize other’s perceptions of one’s self in order to promote individual goals⁴⁶.

Impression management for psychiatric disabilities has largely taken the form of public education programs seeking to replace notions of the abnormal with normal. This is done by contrasting myths of serious mental illness with facts that challenge these myths. The normalcy frame is often used in social marketing campaigns addressing stigma. Australia’s *beyondblue* demystifies treatment by framing it as similar to other medical interventions.

Despite the promise of normalcy campaigns, there may be unintended effects. People with mental illness are fundamentally told to keep aspects of their identity secret. There are consequences to suppressing identity that harm a person’s mental and physical health, relationships and well-being⁴⁷. Despite the risks, coming out has generally been found to yield improved mental and physical health for gays, lesbians, bisexuals and transgender (GLBTs)⁴⁸. Keeping secrets only worsens health and wellness.

What does research suggest about identity and coming out for people with mental illness? Some people who identify with their mental illness may show lower self-esteem and greater pessimism⁴⁹. However, effects of illness identity are influenced by perceived legitimacy of mental illness stigma⁵⁰. Those who identify with mental illness, but also embrace the stigma of their disorder, report less hope and diminished self-esteem. Conversely, those whose sense of self prominently includes their mental illness *and* who reject the stigma of mental illness not only show more hope and better self-esteem, but enhanced social functioning as well.

Identity can have positive or negative valences. People with mental illness may describe themselves negatively in terms of their distress, failures or symptoms. People might try to alter this kind of self-image in psychotherapy, spiritual endeavors, or related activities. Mental illness identity can also be posi-

tively valenced, leading to a sense of pride⁵¹. People experience pride in achieving a standard recognized by their culture (e.g., a medal for the runner) or set by themselves (e.g., a personal best race time). Overcoming challenges of mental illness, withstanding related societal stigma, and demonstrating a sense of resilience may lead to identity pride.

Pride also emerges from a sense of who one is; ethnic pride is an example. “I am Irish American” does not suggest any accomplishment *per se*, but rather an additional answer to the person’s search to understanding “Who am I?”. In this light, mental illness whose challenges have been overcome may be an identity of which some individuals might be proud.

This kind of identity promotes authenticity and recognition of one’s internal conceptualizations in the face of an imposing world. This might take the form of group identification. People with mental illness who more highly identify with “the group” are less likely to experience harm to self-esteem or self-efficacy as a result of internalized stigma⁵².

What then becomes the goal of stigma change programs? Might the public need to acknowledge positive aspects of some people’s mental illness identity and do this by standing in solidarity with them? Solidarity has two meanings here. First, research suggests that people with a stigmatized condition gain strength through association with peers: solidarity in a microcosm of the world. More broadly, however, it is the experience where the majority stands with people who are publicly out with their stigmatized identity: I am in solidarity with people in recovery.

The task that remains for future research and advocacy is to identify when normalcy or solidarity may be most useful for tearing down stigma. Perhaps normalcy messages are valuable to public service campaigns seeking to decrease the stigma of treatment by representing psychotherapy as “just like a visit to the family physician”. Perhaps solidarity is especially poignant for the person struggling with self-stigma, seeking a group of peers with whom to stand proud.

Self-stigma: whose problem is it?

There is one unintended lesson worth learning in terms of tackling self-stigma. Educational and cognitive-behavioral strategies approach self-stigma as “the person’s problem”, rather than a problem of a society that breeds public stigma, prejudice and discrimination. As a result, educational and cognitive approaches may unintentionally pathologize the experience of self-stigma, framing internalized stereotypes as irrational beliefs that reside in the person^{53,54}. Irrational beliefs demand professionally led treatment to correct dysfunctional cognitions. Pathologizing self-stigma may unintentionally promote secrecy, suggesting that people should not disclose mental health experiences.

The harm of sending people back to the closet was reviewed above; strategic disclosure programs have emerged to address this harm⁵⁵. *Coming Out Proud (COP) to Erase the Stigma of Mental Illness* is a three session peer-led program helping to: a) consider the

pros and cons of disclosing in differing settings; b) learn relatively safe ways to come out; c) and craft one's coming out story⁵⁶.

Two randomized controlled trials have documented benefits of COP. The first showed that participants completing COP, compared to a control group, recognized more benefits to disclosure and less need for secrecy⁵⁷. This in turn was related to diminished stress related to self-stigma and disclosure, as well as being more willing to ask for help when in need. In the second, multisite study, women who completed COP showed significant reductions in depression compared to those in the control group⁵⁸. These effects were mediated by significant reductions in self-stigma and stress related to self-stigma. In addition, COP completers showed significant increase in perceived resources to deal with stigma compared to the control group.

Strategic disclosure sends a different message than education and cognitive therapy. COP says that people with mental illness do not need to pass as normal nor conform to expectations based on self-stigma. Disclosure demands solidarity; that the public accepts and empowers friends, neighbors, coworkers and other acquaintances with mental illness.

WHAT MIGHT PSYCHIATRISTS AND OTHER MENTAL HEALTH PROVIDERS DO?

If progressive people seek to tear down social injustices, what is the role of White progressives in correcting racist attitudes against Blacks? Or men in promoting opportunities for women? Or heterosexuals in addressing the social injustices experienced by the GLBT community?

People seeking to right social injustices are energized, wanting responsible roles in tackling these wrongs; they are vital resources for changing the social dialogue. A tough lesson, however, is for Whites, men and heterosexuals to pursue these goals from the back seat. Blacks need to be at the fore of the pursuit of racial justice; women of seeking gender equality; GLBTs of establishing gay rights. In the absence of Black, female and GLBT leaders, efforts to tear down racism, sexism and homophobia fail to capture the dynamic agenda of the community they are meant to empower.

Even more, righting stigma is fundamentally a task of power; Blacks, women and GLBTs need to hold the power. Excluding people from these communities from leadership unintentionally serves to disempower them.

So what might psychiatrists and other providers do to correct mental illness stigma? Start by getting into the back seat. People with lived experience need to be driving the effort to erase the stigma of mental illness. *Nihil de nobis sine nobis* ("Nothing about us without us") is an expression believed to have arisen in Central Europe during the Enlightenment which affirms that no policy or action should be taken about a group without full participation of that group. It is a slogan adopted by disabilities rights groups around the world. People with mental illness need to lead efforts to set policy and actions that affect their lives. This is consistent with what research has

shown about changing public stigma^{59,60}. It is not the professional expert teaching facts of illness that changes stigma, but contact with people sharing stories of recovery.

Moving to the shadows to take a supporting role has been a hard lesson for professionals, especially when society charges them with leading health systems that provide the lens for understanding people with mental illness. However, the professionals' expertise in managing service systems is not synonymous with impacting the social sphere in which those systems operate. This is an especially poignant issue when considering where mental health professions land in response to surveys on public stigma.

Comprehensive reviews show that consumers and families often describe mental health professionals as more likely to focus on the disease while ignoring the person^{61,62}. As many as half of professionals failed to endorse recovery as an outcome for serious mental illness⁶³. Mental health providers often endorse stereotypes about mental illness, including perceptions of dangerousness, unpredictability and blame^{64,65}. The point here is not to chastise professionals; stigmatizing the stigmatizer serves no benefit. Sensitivity to the issue, however, is likely to make professionals better supporting partners in erasing stigma.

Sitting in the back seat is neither irrelevant nor impotent. Mental health providers have significant resources to bring to anti-stigma efforts. They have a certain credibility in the public sphere. Professional voices of hope and self-determination behind a person's story of recovery, instead of gloomy prognosis that often colors media images, exponentially advances anti-stigma goals. In the process, providers may be able to rally other opinion leaders to counter stigma. One example of effective partnership goes back to President G.W. Bush's New Freedom Commission. That commission was a collection of people with lived experience, providers and other stakeholders charged with crafting a vision for mental health services moving into the new millennium.

There are service providers with their own story of recovery. Professionals advocating through their experiences as a service recipient may hold an especially powerful role in the stigma change agenda. Some professionals stepped up to share their stories in the recent book *Coming Out Proud to Erase the Stigma of Mental Illness: Stories and Essays of Solidarity*⁶⁶. Psychiatrists and other mental health providers can stem the course of stigma when embracing roles like these.

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