Commentary

Is Stigma a Stigmatizing Word? A Political Question for Science

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Abstract

Asserting *stigma is a stigmatizing term* is a political statement, a position to which some social scientists may object. They may counter that allowing politics to bleed into an important scholarly question like this will undermine the quality of emerging answers. In this paper, we summarize what many sociologists and philosophers of scientific knowledge maintain; science and its methods are inextricably intertwined with political agendas. This is demonstrated by showing classic examples from astronomy as well as more relevant ones from medicine and psychiatry. Community based participatory research is an excellent vehicle for blending political opinion with scientific method so community based participatory research principles and practices are briefly reviewed, especially in terms of an anti-stigma research agenda. Ironically, we believe recognizing the limits of science for the stigma-is-a-stigmatizing-word question is by no means freeing for advocates. The community of stakeholders invested in this issue still need to deal with the political realities of their diversity and the challenge of developing consensus about stigma as a term and, more importantly, how to erase it.

Keywords: community based participatory research, political agenda

Is Stigma a Stigmatizing Term? A Political Question for Science

Is stigma a stigmatizing term? This can be a challenging question for a journal like *"Stigma Research and Action."* There are scholars who worry this question and the seemingly radical responses that might follow, take a very important construct out of science and into the political world with all the biases and agendas the latter sphere entails. However, we are more optimistic about the political ramifications of advocacy decisions like these, a case that is made herein by reviewing the sociology of knowledge which has examined social biases in scientific investigation. We attempt to shed light on these biases with historical examples cited by philosophers of science that can be applied to the debate on stigma. Examples are also provided that are specifically germane to the sociology of psychiatric science. We believe that research inescapably serves a political endeavor and this is not a damning conclusion but a reality that needs to be explicitly incorporated into the scientific enterprise. Community-based participatory research is one such way where advocates fully partner with investigators in studies; community-based participatory research is briefly considered here. Acknowledging science as politic is not all good news for the advocate. Politics must occur among a diversity of perspectives; advocates rarely speak with one voice, and hence striking *stigma* from the discussion, and replacing it with a seemingly preferred construct like social inclusion, may be neither consensual nor easy.

The Politics of Scientific Knowledge

Many philosophers believe scientific endeavors tainted by social and political agenda are intrinsically spoiled

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(Hempel, 1966). In fact, one of the goals of the scientific method is to provide guidelines so that empirical pursuits are not biased by seemingly irrational prejudices. The success of science and engineering results from products that transcend the transient concerns, fads, or fashions of a contemporary society. Some sociologists and historians of science believe such rigid positivism is not justified (Bloor, 1976). Sociologists of scientific knowledge view empirical research as social activity, seeking to make sense of its endeavors using political, historical, economic, and cultural theory (Glaser & Strauss, 1967; Feyerabend, 1981a,b). The sociology of scientific knowledge is sometimes viewed as a narrower effort of the sociology of knowledge, focusing on social constructions relevant to the development of all knowledge (Durkheim, 1912; Foucault, 1972).

Thomas Kuhn (1962) nicely illustrated socio-political factors that impact science by describing the influence of Medieval Catholicism on astronomy. Namely, a religion-driven belief in a human-centered cosmos served to suppress theory about a sun-centered solar system for centuries. Copernicus proffered one such perspective which he strategically decided to not broadly discuss. Galileo followed 100 years later with ever more compelling evidence to support heliocentric theories, but, failing to heed Copernicus' example, distributed his ideas widely suffering virulent responses from the Roman Inquisition as a result. The impact of socio-political concerns is not just to suppress important ideas; these kinds of concerns also lead to methods which yield amazingly awkward models to sustain the *status quo*. Egyptian astronomer Ptolemy, for example, was only able to explain planetary orbits from a geocentric perspective with ideas of *deferents*, *epicycles*, *equants*, and *retrograde motion*, bizarre concepts that were almost entirely cast aside with Galilean theory.

Kuhn's example seems to yield a two-point moral. First, socio-political pressures indeed influence science. But, second, this influence appears to largely be egregious, which would seem to call for further separation between politics and science by continued evolution of methods of inductive reasoning. Put another way, the independent scientific method is what finally shed light on the errors of geocentric astronomy embraced by Medieval Europe (Hacking, 1981). There are, however, examples when method *per se* maintains a societally-derived concern. Consider this one on randomized controlled trials in clinical sciences.

A common expectation in psychiatric research is Drug X will decrease depressive symptoms. Psychiatric researchers (often with the well-intentioned investment of pharmaceutical companies) propose hypotheses like this based on their careful (logical, rational) analysis of existing research literature. But with the conspicuous emergence of concerns regarding conflicts of interest

(Rothman *et al.*, 2009; Silverman *et al.*, 2010), psychiatric scientists realize some clinical expectations and the information on which they are based might be biased by fiduciary relationships with drug companies driven by responsibility to their corporate board. One might think randomized controlled trials could trump these potential conflicts but not always given the probabilistic nature of clinical research. Namely, randomized controlled trials support hypotheses based on statistical significance and 0.05 alphas. We seem to know Drug X works when it is shown to significantly improve depressive symptoms compared to a control group. But the heart of the hypothetico-deductive method prevents us from showing Drug X is ineffective. This is the basic warning commensurate with the null hypothesis; namely, science cannot reject nonsignificant findings. Failure to achieve 0.05 statistical significance makes it unable to say anything about drug effects at the center of a randomized controlled trial. When a hypothesis is not supported, we do not know whether this means a drug does not work, or whether measures and methods were ineffectual, or theory was incomplete. Hence, the accumulated body of knowledge from randomized controlled trials can really only tell us that a medication is effective and hence worth purchasing.

It is important, by the way, to note this state of affairs is contrary to one of the primary principals of the philosophy of natural science: falsifiability. Popper (1934) described falsifiability as the unique quality that distinguishes science from other knowledge paradigms, perhaps most notably rational and phenomenological philosophies. One of the problems in critically analyzing the latter philosophies is the seeming inability to produce evidence that discounts any of its assertions. The heart of science, so Popper suggests, is the ability to find evidence that shows a theoretical expectation is NOT supported. Hypothesis testing via randomized controlled trials cannot do that.

Consider a third example of science and politic especially germane to the ideas of this special issue. The original notions of Emil Krapelin (1921) and Eugen Bleuler (1911) about schizophrenia being marked by an unavoidable deteriorating trajectory undermined subsequent descriptions and study of processes related to recovery for people with this disorder. An unavoidable downhill course was at the core of diagnosis in the first Diagnostic and statistical manual of mental disorders (DSM) (American Psychiatric Association, 1952) as well as DSM-II (American Psychiatric Association, 1968). It was less explicit but still palatable in DSM-III and DSM-IIIR (American Psychiatric Association, 1980, 1987), and even DSM-IV (APA, 1994). The DSMs are important as compendia that represent research and best opinion about psychiatric illness. As such, they influence insurance, research, treatment, and training

agenda, all professional and hence socio-political in impact.

There is now long-term follow-up research that shows the prognosis of schizophrenia is far more benign than Kraepelin believed, with research suggesting about two thirds of people with the diagnosis are able to achieve the kinds of vocational and independent living skills marking success in most adults (Hopper, Harrison, Janca & Sartorius, 2007). Of course, we should always be careful about presenting a line of research as unequivocal with some studies further describing the complexity of the course of schizophrenia versus affective disorders (Möller *et al.*, 2010). However, the consensus is still compelling; people do recover. Yet despite this consensus, and perhaps still troubling, is the not so rare tautological opinion heard at professional conferences and found in the practice literature that if people were *correctly* diagnosed with schizophrenia, then they would not overcome their symptoms and disabilities.

This whole debate is put further into perspective when considering the parallel, largely political assertions of consumer advocates (Ralph & Corrigan, 2005). Advocate perspectives on recovery are largely derived in reaction to Kraepelinian notions of prognosis and its injuries to a person's sense of hope. Psychiatrists, psychologists, and other mental health professionals learned as recently as 10 years ago that responsible clinical conduct was to teach and convince patients and their families that the downhill course of schizophrenia is unavoidable, that the prognosis is universally poor, and that the achievement of work and independent living goals is impossible. Many consumer advocates argued this advice had as debilitating an impact as the illness itself (Chamberlin, 1977; Deegan, 1988). Research has since begun to provide empirical evidence for this (Corrigan, Salzer, Ralph, Sangster & Keck, 2004; Corrigan *et al.*, 2005). Even more have been socio-political statements from governments and NGOs meant to highlight recovery as a first principle in contemporary mental health care; one important example in the United States was the 2003 report of President George W. Bush's New Freedom Commission setting the agenda for mental health care since.

The primary goal here was to foment doubt among the politics versus science skeptics. Seemingly inviolate principles in the scientific method can be influenced by external social agenda. But, before proceeding let us be clear on one point. We are not among the ranks of scientific nihilists, proposing to throw out methods with the bath water (Nietzsche, 1882; Müller-Lauter, 2000). Ours is an age of evidence-based practices, and rightly so, doing research that finds out what does and does not work in terms of helping people with serious mental illnesses recover (Drake & Bond, 2007; Drake, Bond

& Essock, 2009). Among many goals, this research is meant to influence public policy for distributing limited resources to services that best impact recovery goals (Gambrill, 2006). The current portfolio of methods to do this kind of research is broad – including both quantitative and qualitative approaches varying significantly in guiding principles and practices. Central to this portfolio to serve good science and wise politic is community based participatory research.

Community Based Participatory Research

Community Based Participatory Research, also known as participatory action research in some of the disability-research literature, is a research agenda that includes consumers and other stakeholders as full partners with investigators in all aspects of the scientific evaluation (Rogers & Palmer-Erbs, 1994; Minkler & Wallerstein, 2003). Community Based Participatory Research rests on two principles: perspective and politic (Minkler & Wallerstein, 2003). First, the diverse backgrounds and varied perspectives inherent in Community Based Participatory Research infuse theoretical understanding and corresponding research design. Second, advocates flex their political power by consuming research findings, integrating them into policy, and using their authority and networks to realize important change.

What then does the Community Based Participatory Research team do? Similar to administrative councils of any human service program, the Community Based Participatory Research team is responsible for all activities related to research on stigma and stigma-change programs. This approach signals a paradigm shift for many researchers (Christopher, Watts, McCormick & Young, 2008; Bogart & Uyeda, 2009). Basic to their work under Community Based Participatory Research, social scientists choose to *engage* with other stakeholders in all aspects of effective evaluation. This includes understanding the stigma problem, describing corresponding anti-stigma approaches, delineating methods and measures meant to test the approach, collecting and analyzing the data that emerge from the design, and making sense of the findings. Indeed, *engage the stakeholder* is not sufficient as a descriptor. Partnership is more appropriate; scientist and consumer share all decisions about a study. This means the researcher needs to educate stakeholders about key aspects of the research approach (Chene *et al.*, 2005; Bogart & Uyeda, 2009). However, Community Based Participatory Research is not a unidirectional process suggesting consumers are receptive vessels to investigators. Stakeholders, in turn, are responsible for educating researchers about the socio-political significance of the goals of their work.

Heretofore, we have been using the generic *stakeholder* in describing Community Based Participatory Research. Who is this? First would be consumers of mental health services, though consumer is not a homogeneous construct by any means. Advocates with mental illnesses have been alternatively labeled consumer (the person using mental health services), ex-patient (in part, suggesting no longer needing treatment and, in part, seeking to distance oneself from the mental health system), and survivor (people who have not only overcome their illnesses, but endured the treatment) (Covell, McCorkle, Weissman, Summerfelt & Essock, 2007). Approach to the mental health system and therefore to stigma change varies by role, with survivors, for example, likely to be more critical and skeptical of the system than those who understand themselves as current consumers of care.

Other stakeholders may need to be included in a Community Based Participatory Research effort. Family members of people with serious mental illnesses often have different priorities than relatives with the illness. Family takes many forms; often parents, but also siblings, children, and spouses. Nature of the kinship might impact Community Based Participatory Research perspectives. Service providers may be valuable members of a Community Based Participatory Research team and are likely to vary in perspective by discipline and authority (e.g., physicians usually have legal authority on multidisciplinary teams). If a central strategy for stigma change is targeting persons in powerful roles, then representatives from these groups also would be very useful. For example, it would be important to include employers in an anti-stigma research project on hiring people with mental illnesses. Who better knows the prejudice and discrimination which employers may hold against individuals with mental illnesses?

Diversity also speaks to the demographic of the Community Based Participatory Research. Research suggests stigma and stigma change vary by ethnic group (Farina, 1998). This is a complex relationship however, with effects depending on whether ethnicity reflects the stigmatizer or the stigmatized (Corrigan & Watson, 2007; Rao, Feinglass & Corrigan, 2007). Although unaware of similar research, I would imagine faith-based community, sexual orientation, physical disability, and socioeconomic status are also important influences on stigma. This would beg for inclusion of a demographically diverse group on the Community Based Participatory Research team. This goal needs to be balanced with the necessity to keep group size manageable so team members can be full and vocal partners.

Consensus?

Here it is asserted that considerations about seemingly scientific phenomena by nature include political agenda. Hence, we believe it totally appropriate for politics to have a significant role in deciding the question of this series: *Is stigma a stigmatizing word?* This might seem to suggest a facile process: anti-stigma advocates come together, recognize pernicious effects of a term like stigma, ban it, and seek more progressive ways to move forward with better language. This is likely to be easier said than done. Social scientists and activists know that political movements are more effective among homogeneous groups (Parekh, 2002); it is simpler for one minority class to agree on a political action than obtain accord across several groups. As we discussed in the Community Based Participatory Research summary, mental health and recovery advocates are a diverse lot, so it will be challenging for any community of these advocates to forge clear consensus. This may be especially challenging for the group of consumer advocates tackling *stigma as a stigmatizing term* with some segments of the community actually at odds with the perspectives of others. *Survivor* groups, for example, often frame psychiatry in the most egregious light and believe those who identify themselves as consumers of care may be blind to the injustice, perhaps even *Uncle Toms* for psychiatry. Consumer and family advocates often differ, especially on issues about mandatory or *coercive* services for people believed unable to care for themselves.

An empirical approach might be used to inform this process; survey a diverse group of advocates to identify trends for and against various terms. The results, however, may be surprising and disappointing. Consider what research suggests in terms of how to refer to people with mental illness: patients, consumers, people, or clients. Findings have fairly consistently been unable to show antipathy or preference for any specific terms (Mueser, Glynn, Corrigan & Baber, 1996; Penn & Nowlin-Drummond, 2001). Hence, science may provide some support in questions like these, but more likely limited information overall. At the end of the day, the community of advocates is left weighing these brief insights against the broader agenda of social justice. We need to keep our eyes on the prize. Coming to consensus on whether stigma is a good or bad term is, in our opinion, a small part of the larger battle. Advocates need to develop some larger sense of what is the problem wrought by stigma or its proxies: prejudice and discrimination. Even more important, they need to come together to map out varied avenues for approaching and extinguishing the experience.

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