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Use data to challenge mental-health stigma

Web surveys of attitudes towards mental illness reveal the size of the problem — and offer a way to find fixes, says Neil Seeman.

The US National Institute of Mental Health considers stigma to be the most debilitating aspect of a mental illness. It is easy to see why. Stigma increases mental distress and leads to shame, avoidance of treatment, social isolation, and, consequently, a deterioration in health.

What form does this stigma take? Is it decreasing for mental illnesses such as depression, as claimed by some media articles? How can it be combated? We don't know the answers to those questions. That is partly because not enough people have asked them — and partly because not enough people have answered them. Surveys are expensive, and funds, especially for research on mental illness, are limited.

Surveys in the old days saw pollsters with hand-held clipboards quizzing shoppers in department stores. This gave way to the ubiquitous telephone survey. Today, the Internet affords ever more ways to collect survey data. Some years ago, I developed a way to ask questions in an efficient and global manner. It is called Random Domain Intercept Technology and it relies on people — like you — making mistakes while browsing the Internet. Mistyped URLs and broken web links trigger the survey, and invite the user to participate.

Unlike surveys in which people are given cash or rewards to answer questions, this method does not allow for a long-form questionnaire, although it can break down long surveys into shorter mini-surveys. It permits brief questions — often 8 to 15 of them — to be asked, and answered on a voluntary, non-incentivized basis by large numbers of random and anonymous people using the Internet. And that means almost everywhere in the world.

From September 2013 until May this year, we used the technology to ask some simple questions about mental illness and stigma. More than 1 million people from 229 territories responded. Their responses offer a unique and real-time snapshot of how the globe thinks about the estimated one-quarter of its population who will experience mental ill health (N. Seeman *et al.* *J. Affect. Disord.* **190**, 115–121; 2016).

The survey requested age and gender, and then asked two specific questions. First, is there someone you interact with every day who suffers from mental illness? (This may include psychosis, depression or addiction.) And second, are people who suffer from mental illness any of the following: more lazy, more violent, suffering from a condition as serious as physical illness, the victims of bad parenting, or able to overcome their challenges through 'tough love'?

In developed countries, only 7% of respondents thought that people with mental illness were more violent than the general population. In remarkable contrast, about 15% of those in developing countries thought that people with mental illness were more violent. Although 45–51% of respondents from developed countries believed that mental illness is similar to physical illness, only 7% of the same people thought that mental illness can be overcome. It seems that the understanding that mental illness has a biological cause makes the public more, rather than less, pessimistic about outcome. This has been reported previously, and is, at first glance, counterintuitive. Attributing illness to genes takes away blame, but at the same time, takes away hope for change.

Although the identity of individual respondents is unknown, the overall reproducibility of responses from any one region is high. When the same questions were posed every month in India for 21 months running, 10% of respondents each time reported that people with mental illness are more violent than others.

And despite the fact that mental illness is often a taboo subject, the anonymity of the survey facilitated consistent answers. In China, for example, people with mental illness are often viewed as bringing shame on their family. The 'loss of face' associated with mental illness there and in many developing countries attaches not only to the ill person, but also to family members. In this context it makes sense, therefore, that people with mental illness are kept at home, and this may explain the high proportion of people in China who reported having daily contact with a mentally ill person.

The approach I describe can uncover views on any topic held by those in Internet-enabled areas, currently 43% of the planet. And it can allow for 'before and after' surveys, assessing the effectiveness of population-wide interventions.

For instance, it would be of immense value to repeat this stigma survey in a region that has introduced a public-education anti-stigma campaign. The tool is not limited to stigma — in the field of mental health, for instance, it can probe suicidal ideas and, again, evaluate a suicide-prevention intervention. It can probe symptoms of post-traumatic stress disorder in the wake of a disaster (such as a hurricane or the Paris terrorist attacks) and test ways to mitigate these traumas.

Measuring a social problem on the scale of mental-illness stigma does not make it go away. But at least it shows us the size of the challenge — and could very well help to find ways to fix it. ■

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