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Patient Commentary: Online screening for depression—old (paternalistic) wine in new (digital) bottles

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When you are in mental and emotional distress, part of the agony is because the mind cannot make sense of what is happening inside or outside. In this situation I have wanted a diagnosis to help explain what I am going through and to give a semblance of choice and control. If what I am feeling is something others regard as real, maybe it becomes more amenable to being fixed. Diagnosis is a key that might unlock the prison cell of suffering.

On the other hand, I have also hated being given a diagnosis. Questions such as whether I'm "really" depressed ignore my wider unhappiness and what matters in my life. Diagnostic labels imprison me as a passive patient rather than consider me as a person.

So, does Google's offer of the PHQ-9 test help to unlock or lock the prison cell? This diagnostic tool focuses on physiological and biomedical symptoms. It puts firm emphasis on dysfunction and frames distress from the outset as an illness. "Significant" scores position your problems as being amenable to doctors' treatment. Maybe that's fair enough, but let's look at context.

The underpinning belief here—for doctors and other advocates of such tools—is that there is undertreatment of depression in the community and that we should encourage more people to access care.

Wellbeing versus neurotransmitters

This is fine if there is an acknowledgment that my wellbeing is as much to do with being loved—having a meaningful life and belonging—as to do with the state of my neurotransmitters, and if there is the right sort of support, control, and choice in what happens next.

The default option in my experience, however, has always been to give drugs. It is hard to see this changing. The larger proportion of a dwindling healthcare pot will inevitably be carved up between institutional, professional, and industrial interests.

Social care cuts and lack of investment in community networks and peer support mean that there are few means of keeping well or getting well in settings outside the formal healthcare system. True, there are amazing schemes in a few places that help people back to work,² recovery colleges providing education as a route

to recovery, and so on, but they are not often part of mainstream service provision. And once you enter the consultation room and the risk averse medical sphere, choices dwindle. It's going to be drugs or—if you're lucky—a narrow range and limited number of counselling sessions.

Diagnosis for patients

Other ways are emerging to make a more meaningful diagnosis, such as psychological formulation. This is a narrative process in which people work with a professional to make sense of their difficulties in the context of their life and social circumstances.³ But how much room might there be for this sort of dialogue if Google's approach spreads? In effect, the nature of the PHQ-9 test and the restricted range of choices mean that Google is driving people quicker down the path to big pharma. Remember, Pfizer funded the development of the tool.

What about stigma? If my odd state is deemed to be a real medical condition picked up by an online diagnostic tool, then I should surely feel less shame? This is a misplaced belief, but understandable, in that there seems to be a societal effort to equate mental health problems with physical ones. It fits with a longing by psychiatrists to be seen as more scientific. But I believe mental health problems are much more bound with psychosocial explanations, uniquely cutting across the boundaries between emotional and physiological causes.

This is perhaps why there is a history of ambivalence towards diagnosis among people with mental health problems. Labelling, control, stigma—these are carved deep into the psyche. I am a person with rights, not a defective brain to be normalised.

I am not anti-drugs (I take citalopram and pregabalin). I am pro-choice. Widespread use of biomedically framed diagnostic tools plus a lack of alternatives spreads a world view that sees me as a symptomatic patient rather than a whole human being. This threatens to increase stigma.

Ironically, people for and against tools such as this share similar beliefs: more awareness (of symptoms) is good, better (medical) diagnosis is good, doctors and treatment (mainly drugs) will save us. Google, in effect, is serving up old (paternalistic) wine in new (digital) bottles.

Wise creatures

But here's the good news. People who experience distress are wise creatures. Trauma has damaged them. Sensitivity has left them more permeable than most to the world and its terrors. If they are Googling, curiosity and questioning will take them elsewhere. If they can more easily find alternative sensemaking, access to help to get back on their feet, safe spaces to meet, community based support, and peers who can go on the journey with them, there is hope. We will need patient entrepreneurs, peer support advocates, and community development activists to design tools that will do all this.

However, this change will happen only if service users have power and are equal partners in policy and planning, in design and delivery in the NHS, and with corporations like Google, so that decisions about allocation of resources and information governance are made together. We should be partners for change. Only then will online tools be a key that unlocks sensemaking, choice, and control.

InHealth Associates provides support for patients to be partners for change. David Gilbert blogs at www.futurepatientblog.com and is on Twitter, @DavidGilbert43. He is also patient director at Sussex Musculoskeletal Partnership (Central). This article is written in his personal capacity.

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