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THE CONVERSATION

How genetic testing is swelling the ranks of the ‘worried well’

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Genetic testing and screening is increasingly becoming a presence in our lives. Daily news reports discuss new associations between genes and common conditions. And these associations are used to calculate risks for individuals who have the genes for the conditions, but don't display any symptoms.

In essence, these people become the “worried well”, a group of people not yet ill, but at risk of developing diseases.

Genetic tests and over-diagnosis

Once restricted to the domain of the clinic, genetic testing is now available to most people, either through their doctor or via the internet. There are a variety of tests in the market, some of which can provide risk estimates associated with complex common diseases such as diabetes, obesity, Alzheimer's disease and cancer.

A major concern with such tests is that they're the beginning of a path toward over-diagnosis, where the potential to develop a disease or being at risk for the disease is strong enough to constitute a label of sickness.

[Over-diagnosing](#) includes, but is not limited to, widening disease definitions, early detections of abnormalities that may or may not cause symptoms or death and the use of increasingly sensitive technologies that detect “abnormalities,” the causes and consequences of which are unknown at this time.

Genetic testing and screening could be seen as the ultimate test (the most fundamental part of one's body and life is used to classify a person as ill or potentially ill), so what are the implications of using this technology to assist in diagnosing and classifying people?

The worried well

For the individual whose health status is in question, genetic testing has the potential to give them a label, adding them to a growing class of citizens, the [“worried well”](#). These people are not ill as they don’t display symptoms of the condition with which they are labelled. Nor are they clinically diagnosed as having the disease in question. Instead, they are at a pre-phase, they are now genetically at risk for a particular disease. But the date, time, and list of symptoms they’re likely to experience or the severity of the illness are yet to be determined.

For an individual seeking an explanation for their state of (ill) health, over-diagnosis based on their genetics can confirm their fears that something *may* be wrong. This means they are now expected to fulfil personal, familial and societal roles traditionally associated with being sick while not actually displaying symptoms of illness.

Along with this new role, the worried well are also endowed with benefits traditionally reserved for people who are unwell – special levels of treatment, access to certain medical care and different levels of expected behaviour. And, to know that you are at risk for a disease means you are also now responsible for taking action to reduce or subvert your likely future of ill health. Not to do so could render you morally culpable for any ill-health your future may hold.

Social implications

For society, the implications of genetic testing and over-diagnosis is the opportunity cost of treating the genetically at risk rather than those who are symptomatically ill. In the struggle for scarce resources, decisions are made between who and what diseases will receive the funds they desperately need. At this intersection, diagnosis plays a pivotal role in what and who is a beneficiary of the resources available and how they can best be procured.

One potential (and limited) benefit of these tests is the creation of new markets for drugs or preventative treatments that can flourish as more people are labelled with conditions. But with health-care costs increasing and the need for rationing a central concern, there’s also the danger that resources will be diverted from public health measures that have a chance of preventing genuine illness in favour of treating [“pseudodiseases”](#).

If we are not careful, we may let the benefits of a sick label outweigh the benefits associated with being healthy. In this new millennium of advancing technologies, there’s cause for concern when the race is no longer toward who can be described as healthy, but who can be classified as ill or diseased.

At the time of writing this article, Jacqueline Savard was a PhD candidate in the [Centre for Values, Ethics and the Law in Medicine \(VELiM\)](#), the University of Sydney.