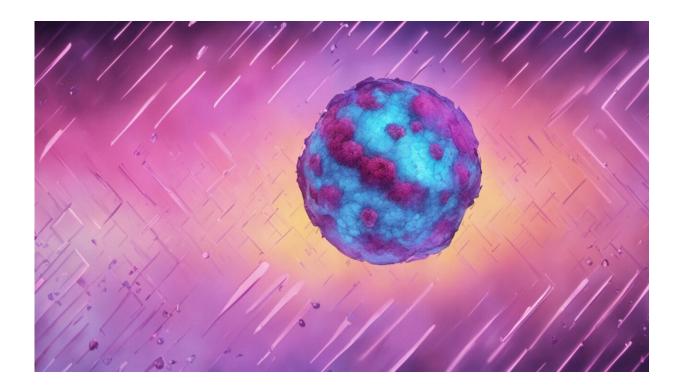


Online cancer fakers may be suffering a different kind of illness

July 23 2015, by Peter Bat And Julie Ellis



Credit: AI-generated image (disclaimer)

Trust is very important in medicine. <u>Increasing numbers of people</u> are using the internet to manage their health by looking for facts about specific illnesses and treatments available. And patients, their carers and the public in general need to trust that this information is accurate, reliable and up to date.



Alongside factual health websites, the internet offers discussion forums, personal blogs and social media for people to access anecdotal information, support and advice from other patients. Individuals share their own experiences, feelings and emotions about their illnesses online. They develop relationships and friendships, particularly with people who have been through illnesses themselves and can empathise with them.

Some health professionals have concerns about the <u>quality of medical</u> <u>information on the internet</u>. But others are advocating that patients <u>should be more empowered</u> and encourage people to use these <u>online</u> <u>communities</u> to share information and experiences.

Within these virtual communities, people don't just have to trust that the <u>medical information</u> they encounter is factually correct. They are also placing trust in the other users they encounter online. This is the case whether they are sharing their own, often personal, information or reading about the personal experiences of others.

Darker side to sharing

While online sharing can be very beneficial to patients, there is also a potentially darker side. There have been widely-publicised cases of "patients" posting information about themselves that is, at best, factually incorrect and might be considered deliberately deceptive.

Blogger Belle Gibson built a huge following after writing about <u>being</u> <u>diagnosed with a brain tumour</u> at the age of 20 and the experience of having just months to live. She blogged about her illness, treatment, recovery and eventual relapse while developing and marketing a mobile phone app, a website and a book. Through all of this she advocated diet and lifestyle changes over conventional medicine, claiming this approach been key to her survival.



But Gibson's stories were later revealed to be part of a <u>tangled web of</u> <u>deceit</u>, which also involved her promising to donate money to charities but, allegedly, <u>never delivering the payments</u>.

In one sense, people's trust was broken when they realised they had paid money under false pretences. In another sense, they may have followed Gibson's supposed example of halting prescribed treatments and adopting a new diet and lifestyle when there was no real evidence this would work. But, at a deeper level, people may feel betrayed because they sympathised and indeed empathised with a person who was later revealed to be a fraud.

The truth was eventually publicised by online news outlets and Gibson was subject to complaints and abuse on <u>social media</u>. But there is something about the anonymity of the internet that facilitates this kind of deceptive behaviour in the first place. People are far less likely to be taken in by this sort of thing in the real world, but they are online. And it destroys people's trust in online resources across the board.

Trust in extreme circumstances

Despite this, the moral outrage generated online by this kind of extreme and relatively isolated incident may be misplaced. There <u>is evidence</u> to suggest that people who do this may actually be ill but it's a very difference sort of illness.

Faking diseases or illnesses – often described as Munchausen's syndrome – is not unique to the internet and was reported long before its advent. The <u>Roman physician Galen</u> is credited with being the first to identify occasions on which people lied about or induced symptoms in order to simulate illness. More recently, the term "<u>Munchausen by internet</u>" has been used to describe behaviour in which people use chat rooms, blogs and forums to post false information about themselves to gain sympathy,



trust or to control others.

Whichever way we view people who post such false information, their behaviour raises the question why people with genuine illnesses still share such intimate details when the potential for dishonesty from others is so evident. Our new research project, "<u>A Shared Space and a Space for Sharing</u>", led by the University of Sheffield, is trying to understand how trust works in online spaces among people in extreme circumstances, such as the terminally ill.

We need to know why people trust and share so much with others when they have never met them and when there is so much potential for deceit and abuse. It is also important to identify people who fake illness online if we are to ensure there is public trust in genuine online support platforms.

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