The New Public Care: Seeking Coronavirus Truth through Networked Publics

MAGDALENA GÓRALSKA

Before the pandemic begun the usual turn of events was like that: Beata, an accountant from a mid-size town in Poland has a health problem, or her husband has. She is not satisfied with medical advice given by doctors from either private or public healthcare sectors. She picks up her smartphone (she's 60 but she knows how to use it, alright), she opens her Facebook account, and searches for this health advice group her friend invited her to. It's about herbs, homemade remedies, but also more serious stuff like Ayurveda, TCM, acupuncture, naturopathy, and some less popular treatments coming from conventional medicine, such as taking high dosages of vitamins or getting lymphatic massages. Actually, there are more groups than one, all have thousands of members and dozens of posts daily, each rich with commentary. Expressions of support are the least one gets – the majority of replies are full of advice based on personal experiences, or knowledge gained through one's "own research".

Beata posts her question, finishing it with "Please help, nothing works, doctors are helpless, I AM DESPERATE". An intimate call for help that takes place in the networked publics of social media (Boyd 2011; Papacharissi 2015). A call that could be made to a group of friends, but the digital distance is paradoxical – it makes people feel closer to each other, just as they would be talking face to face, even if they bodies are miles apart.

Now with the virus influencing every aspect of our lives I can see multiple changes to my fieldwork. The different kind of posts have become more visible – the one wondering "what the hell is REALLY going on with the virus?". Numerous theories are exchanged – concerns regarding current anti-pandemic policies, the origins of the virus, the scale of the pandemic, whether the virus exists at all, or why there is limited medical advice on how to prevent getting infected. At beginning, in January and February, I could see the rise in general questions regarding ways to support the immune system against the virus. In March, questions became more COVID-19 related and more politicized, giving group members a chance to share their emotions, fears, confusion, and anxiety. With no consensus of what is the backstory to coronavirus, everybody seemed to have stocked up on vitamins and zinc, but various other solutions to COVID-19 have been circulating across my fieldwork too, in and out of the those groups for weeks now. The majority of these seem harmless, with perhaps a few exceptions. But not everyone thinks it's okay for their advice to circulate, and members of those groups know it – the misinformation label given to alternative coronavirus-cures is strengthening the conspiracy theory which claims that the Big Pharma is trying to eradicate other solutions, so it can profit of the vaccine.

The pandemic has also made the pitfalls of digital communication more visible.

I became interested in knowledge communication about four years ago, seeing how various media and social agents are involved in creating "networked" knowledge repositories, where information constantly circulated between various agents, and isn't permanently embedded anywhere. When it comes to knowledge regarding health, the Web is a place not only for conventional medicine – the multiple online repositories of health advice that is lab-tested, certified, and, most importantly, scientifically proven. It is a safe haven for all those other kinds of knowledge that do not meet those criteria. Those include what some call naturopathy, homemade remedies, TCM, Ayurveda; the list goes on and on.

The pandemic have made those various knowledges exposed – many solutions that are popularly perceived as alternative, or complementary, to the mainstream, science-based medicine can be classified as misinformation, hoaxes, snake-oil cures that aim to mislead and strip of substantial amounts of money the naïve, lay, and desperate public, seeking protection from the dangerous virus. With tech giants taking big steps to curb health misinformation and COVID-10 infodemic[1], I wonder – how will they define what is what? What epistemological guidelines will they follow to define what is misinformation? Is a belief that putting Manuka honey up one's nostrils dangerous enough to get deleted? Or even drinking herbal anti-viral TCM mixtures? Or is it only the conspiracy theories that are being deleted?

Moderation of content that isn't pornography, violence or strictly political disinformation, such as Russian fake news saying that Boris Johnson is in a critical condition[2] is extremely difficult to tackle[3]. Misinformation's grey zone of health advice includes the whole ocean of various alternative, well-wishing cures. One can argue that they are misleading as they give false hope to help against the coronavirus, making people feel more secure than they actually are. Is it unethical to not classify some not-tested and not-scientifically proved immune-boosters as misinforming? Who should decide?

The inquiry into the institutional and expert crisis of the modern state has been a subject of vast scholarly inquiry over the past two decades. Whether the Internet can be blamed or not, one thing I am certain of – my interviewees do not lack an ability to think critically, and that's not the lack of skepticism that makes them trust that they can boost their immune systems with herbs against the coronavirus. It's the healthcare system that has disappointed them by failing to address their need to understand what's happening with their bodies, gain self-knowledge, and implement healing practices that could be complementary to the science-based medicine, even though they are not based on it.

With the coronavirus pandemic across the globe, I ask – what will be the post-pandemic future of health care? And what will happen to those not-scientific health solutions? There certainly is a need for what I have called "the new public care" – the community-care of people seeking health advice "out of the box". Will there be a place for them, or will they be moderated out of networked publics?

ABOUT THE AUTHOR

Magdalena Góralska studies networked health communication since 2016. She is a researcher at Kozminski University, and a postgrad at the University of Warsaw's Institute of Ethnology and Cultural Anthropology.

magdalenagoralska.org.

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[1] https://www.npr.org/2020/03/16/816344301/tech-companies-aim-to-stop-covid-19-disinformation?t=1586439764888
[2] https://www.businessinsider.com/boris-johnson-hospital-persistent-coronavirus-symptoms-russia-ventilator-disinformation-covid-2020-4?IR=T
[3] I wonder more about this enquiry, see here https://medium.com/@maniagoralska/from-content-moderation-to-social-media-censorship-76f5c040c795