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SCIENCE JOURNALISM IN THE AGE OF CROWD: INTERVIEWS

Participatory medicine as a new way to produce medical knowledge

Interview by Filippo Bonaventura

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ABSTRACT: Public communication on health issues on the Internet is not only a matter of popularization of medical information. It deeply deals with narration, conversation and dialogue, which are typical values in the Web 2.0. This interview will emphasize that blogs, forums, wiki are new ways in which population has been reconstructing and integrating medical knowledge. These ways are re-defining medical knowledge by means of unhinging the standard medical communication practices, based on a linear diffusion of knowledge from experts to laypeople.

Information fluxes in the Web is nowadays dominated by social media. Being medical issues an integral part of day-to-day life, they are more and more present in new platforms like Facebook, Twitter, YouTube, but also in ad hoc platforms (PubMed, Medting, PatientsLikeMe...), in which is possible for both patients and healthcare professionals to exchange medical information. This participatory communication practices can, in principle and in general, re-define medical knowledge. This is because of a shift from the traditional medical communication process – namely, peer-reviewed publications in scientific journals and then expert-to-patient communication – toward a broader discussion between medical practitioners and people suffering from diverse disorders or diseases. Web 2.0 is blurring the border between different actors involved in medical issues, and this results in a democratization of medical information. We'll deepen these topics with Denise Silber, expert in medialisation of health in the Web and founder of Basil Strategies.¹

Web 2.0 gives new opportunities to produce and share medical knowledge. Perhaps the most interesting are participatory medicine (which is mostly public-driven) and unreviewed publications by scientists, MDs and practitioners. What are, in your opinion, the epistemological differences between these two instances?

Web 2.0 is about conversation and dialogue. Most unreviewed publications by scientists, healthcare professionals tend to be in the form of personal blogs, comments on forums, wikis, mailing lists. They are generally not a presentation of original research studies. Patients participate in a similar way with blogs and comments, on forums and in lists, and also on sites where they can present their experience with a disease as a narrative.

Last year, in Italy, communication about H1N1 flu dissuaded population from getting vaccinated. How much is trust important in such cases? Are there any others examples in which communication practices influenced citizens' behaviour?

Around Europe, the population lost trust with the official sources during the H1N1 epidemic. These sources were not present in social media and so the conversation carried on without them. I can give an

opposite example, the case of the Global Fund: between May and October 2010, it ran a successful social media campaign about HIV transmission from mother to child.

Are we witnessing a change, due to social media, in the way in which medical information is validated? How can medical information be validated in an environment in which so many voices are involved? What are the new validation criteria?

Surveys demonstrate that people want to validate information they find with their physician. The physician must be open to discussion and not presenting 'definitive truth.'

In your opinion, is participatory medicine more a form of self-expression or altruism?

It's primarily a form of self-expression by the patient. For the healthcare professional, to encourage patient self-expression should be part of their job.

How much is important the dialogue among actors involved in communication about medical issues? Do you think it can produce new forms of medical knowledge? Do you think it can enhance a Nation's democracy?

Dialogue and narrative by patients will produce new knowledge. For example, results of clinical trials on drugs up until now are not reproduced in the same percent in the real world. Now, everyone will be able to access the real patient experience.

Some years ago Amanda Baggs, autistic young woman, posted on YouTube a video showing her condition and her 'language'. The worldwide diffusion of this video demonstrates that social media made it possible to re-define what autism is. From a more general point of view, how can active public participation in communication about medical issues shift the line between health and illness?

Many things are changing as walls are broken down. More people will be made aware of a condition they have and that they did not realize. Some patients now attend scientific conferences. More people can contact specialized experts than before. People are more committed to their treatment, because they are involved actively and not passively...

How can laypeople active in communication contribute to the production and validation of medical knowledge? Are there any significant examples?

Patients donating information about themselves on sites like PatientsLikeMe.com or on lists like ACOR.org further scientific knowledge.

What happens when the open access 'philosophy' (typical of Web 2.0) meets privacy needs? How can people performing participatory medicine protect themselves?

Participating on the Web does raise privacy issues. It is not obvious to try to maintain total anonymity and to provide full details of one's case. Someone reading this could identify you.

I think that we'll be redefining the needs for privacy in the near future.

Notes and references

¹ <http://en.basilstrategies.com/>.

Author

Denise Silber, an American in Paris, is the founder of Basil Strategies, healthcare emarketing and social media consultancy and President of the Association for the Quality of Health on the Internet. She has been involved in eHealth in Europe and the US since 1995, when she launched the first workshops, newsletters and medical web sites. Denise is now equally a pioneer of the 2.0 and social media movement through public speaking, blogging, and the organization of conferences. Denise is a Harvard MBA. E-mail: Denise.Silber@BasilStrategies.com.

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