Biomedical journalism and the challenge of the Internet

Connie St Louis

Introduction

In March 2011 the most powerful earthquake and tsunami in Japan's history caused horrifying devastation in the North-Eastern coast. Along with an apocalyptic loss of life, the entire infrastructure of the region was destroyed, buildings were crushed and communication networks including phone lines went down. However, the mobile Internet was still available and resourceful doctors decided to use the micro blogging tool Twitter to inform their chronically ill patients where they could obtain urgent medicines. In a letter to the medical journal The Lancet Dr. Yuichi Tamura and Dr. Keiichi Fukuda, cardiologists at Keio University School of Medicine in Tokyo wrote: «We were able to notify displaced patients via Twitter on where to acquire medications. These 'tweets' immediately spread through patients' networks, and consequently most could attend to their essential treatments» (Tamura and Fukuda, 2011).

So where did this leave Japan's media? Normally, in disaster situations, the public relies on the media to provide reliable emergency information. In this case they were cut out altogether. Doctors went straight to patients and vice versa using the microblogging site Twitter. It's clear that the actions of the doctors were altruistic and undoubtedly saved lives but what if there had been someone seeking to mislead and deceive patients? It is very difficult to verify the identity of someone on Twitter, a fact evidenced by the number of 'stolen' identities of celebrities, which has resulted in Twitter developing a special authentication process for such cases (Greenfield, 2012).

A recent Pew survey found that the 80% of Internet users have looked online for information about

any of 15 health topics such as a specific disease or treatment, a figure which translates to 59% of all adults (Fox, 2011). In an age of direct marketing, where information is also produced by individuals, medical and pharmaceutical companies are often competing with vested economic interests. It is a good moment for biomedical journalism to reflect on its role and purpose in this new digital age.

What is 'biomedical journalism'?

The biomedical (health or medical) journalist is a multi faceted role, which is a complicated and contested one in the modern world. To understand the tensions in the reporting of biomedicine, it is important to understand the multiple business parameters and knowledge frameworks within which the biomedical journalist operates. They operate within a tightly controlled system of constraining narrative conventions (Nelkin, 1995; St Louis, 2011). The most common role is the one described by Hinnant and Len-Ríos (2009) as 'information brokers', where medical information is communicated to the public. The second and more important role is that of reporter and investigator. The journalist must then conduct investigations, which analyse the distribution of medical resources; scrutinise and call to account both doctors and biomedical scientists (St Louis, 2011).

What was the role, then, of the Twitter users who re-tweeted the Japanese doctors' medicine information? They are amplifying that information, but it's not journalism, because there is no investigation, and no challenge.

And what of those patients who don't use Twitter, or the Internet? Even in this networked age,

and in the country with the highest Twitter usage, many individuals do not 'Tweet" or are not 'online' the average salary of a Twitter user in 2011 in the US was \$75000, and the average age was 45 years old (Fox, 2011). Up-to-date statistics and definitions are elusive, as is the definition of biomedical journalism. An article in the Croatian Medical Journal describes it as reporting medical study results and thereby disseminating this information for the good of humanity (Habibzadeh, 2005): «Not all research findings are useful for all settings. Employing the basic concepts of evidence-based practice we have to examine the current body of evidence to see if it is acceptable to our setting or not. Perhaps, this is a time to extend the concepts of evidence-based practice to the field of journalism -a time for a paradigm shift from eminence-based to evidence-based journalism. We can take the universally accepted standards, customize them according to our own needs, culture and setting and give feedback to the world. In this way, biomedical journalism, the most important aim of which is to improve human health and life, can progress in different parts of the world» [italics text added for emphasis].

Magnifying glass

The main challenge presented by the Internet is that anyone can tweet or re-tweet with no scrutiny of the information. This is especially a problem at the current time, when the media are finding it harder to provide high-quality content due to the ongoing loss of revenue whilst, at the same time, public appetite for health information online is growing and the net is a ubiquitous source of information. As an example, recent research has demonstrated the increasing reliance of diverse publics, notably in the USA, on the Internet as a source of information on science, medicine and technology (Lacroix, 2001; Miller, 2001).

Sophistication and nuance are important here and are skills that journalists should be equipped to provide. Culturally, we now turn to the Internet for a variety of activities: from journal papers, self-published research reports, statements by Internet groups, news media articles, company promotions, and contributing to mailing lists or

Internet news groups. It takes above-average Internet literacy to distinguish these difference types of information and informants from each other, and assess their reliability.

Evidence shows that many of us now consult the Internet for medical information. In research carried out by Fox, 30% of adults reported that they or someone they know had been helped by following medical advice or health information found on the Internet, which represented a 25% increase since 2006 (Fox, 2011). Medical information is now accessible to the wider public without professional mediation, either medical or journalistic. Medline is a database of medical-scientific materials which forms a primary research tool for medical professionals. It can be searched (albeit in a somewhat reduced form) free-of-charge online (US National Library of Medicine, National Institutes of Health, 2012). An early study of the users of this resource in 2001 showed that 30 per cent of users were not researchers, teachers or doctors, but others searching for medical information (Lacroix, 2001).

Trench (2007) amongst others has observed that the Internet outstrips the journalists and media. He suggests that in the current environment, journalists have become irrelevant. The Internet has the benefit of giving the public ready access to medical journals and materials that they have never had access to before.

Are patients empowered?

As part of my preparation for this symposium on 21 September 2011 we interviewed Josephine the paid administrator of a patient forum called BoneSmart (Foundation for the Advancement in Research in Medicine, no date), a website that specialises in providing information for people experiencing hip/knee replacement surgery. When asked where she looks to find health news, and which newspapers, radio, TV, Internet sites does she read or visit, she replied: «I hardly ever look at them! Though they are good for an alert about a new research paper, etc., I would only ever then go to look for the original paper before taking it on board. Some of the items I have seen and read were so full of misinformation or out and out incor-

rect information; they weren't worth the time spent reading them! Principally, I get my information and updates from a subscription to the Journal of Bone and Joint Surgery» (St Louis, 2011) [italics text added for emphasis].

Josephine and the other volunteer members of the forum help each other. They have thousands of visitors per day. She continued: «A forum like BoneSmart is invaluable in enabling patients to compare notes and get some reassurance that their progress is actually quite normal; or, if they are having real problems, to have a group of people lending a sympathetic ear and cheering them on. And from me they can get technical explanations of things that they probably didn't understand from their doctors —a kind of interpreter, if you will!» (St Louis, 2011) [italics text added for emphasis].

The last part of that quote may be surprising for many journalists. Isn't this their role? Haven't they traditionally been the gatherers and reporters of biomedical information for the public? So in the new Internet world is Josephine now a journalist?

There are many other such fora on the web, for audiences and these include, www.healthtalkon-line.org set up by the late Dr. Ann McPherson to allow patients to talk about and their health experiences of over 60 health-related conditions and illnesses; www.ocularmelanoma.org which with a specific disease such as ocular melanoma and those such as org, www.patient.co.uk which offers trusted medial information and support.

Another such forum is called BrainTalk Communities: Online Patient Support Groups for Neurology (Brain Talk Communities, 2012). Braintalk is organised into more than 200 free online groups for neurological conditions, ranging from common conditions such as multiple sclerosis to rare conditions like Mobius syndrome. It was analysed by Harvard neurologist, Dan Hoch, and the website's creator Tom Ferguson, a senior research fellow at the Pew Internet and American Life Project. Their study (Hoch and Ferguson, 2005) found that two-thirds of posts on the website were about sharing information in the relevant disease. More than 200.000 individuals visit the BrainTalk site on a regular basis. Hoch and Ferguson described an observational study in the ways in which E-patients were using this new medium: «What we found

surprised us. We assumed that most interactions would be support related, with some members describing their medical experiences and others offering active listening, sympathy, and understanding. But while such interactions were an important part of the group process, they were observed in only about 30% of the postings. In the remaining 70% of the postings, group members provided each other with what amounted to a crash course in their shared disease, discussing topics such as the anatomy, physiology, and natural history of the disorder; treatment options and management quidelines for each form of treatment: and treatment side effects, medical self-management, the day-to-day practicalities of living with the disease, and the effects of their condition on family and friends» (Hoch and Ferguson, 2005).

Hoch explains his initial concerns over patients sharing medical information in this way. There may indeed be dangers of the public having access to all this material, although it's difficult to find cases of harmful self-diagnoses or self-medication that are result of using online information. Crocco, Villasis-Keever and Jadad (2002) examined the incidence of under reported harm and found very few cases: «Despite the popularity of publications warning of the potential harm associated with using health information from the Internet, our search found few reported cases of harm. This may be due to an actual low risk for harm associated with the use of information available on the Internet, to underreporting of cases, or to bias» (Crocco, Villasis-Keever and Jadad, 2002).

Whilst there is no statutory regulation of the quality of health information that is found on the web. It is surprising that only 3% of all adults say they or someone they know has been harmed by following medical advice or health information found on the Internet (Fox, 2011). This finding has remained stable since 2006 and it is interesting to note that this study also found that 30% of all adults said they had been helped by the health information that they discovered online.

The conundrum of the underreporting of the harms associated with the use of health information available on the Internet highlights an important role for the biomedical journalist. If the lack of cases of harm is due to "underreporting" as sug-

gested by the author of this report then surely this is the moment for the utilisation of the full armoury of investigative skills available to the biomedical journalist.

Though still in its infancy, there are some journalists who are using the full investigative arsenal at their disposal, to produce this kind of reporting. Canadian freelance journalist Tom Koch forced a New York judge to overturn his verdict that the death of a 6-year-old was "accidental". Koch discovered online that the anaesthetic given to the child was known to cause respiratory problems in children. This was in 1994, before the net was as pervasive as it is now. In his analysis of the case Agostini (1997) found that Koch had found the crucial information by an early form of crowd sourcing, a methodology now ubiquitous in social networking. The ability to collate, research and analyse data as well as been able to use the computer to assist reporting is now an essential skills for any journalist.

Health and social media

In the earlier example of the chronically ill Japanese patients who needed their medication during the earthquake and tsunami, Twitter was vital. But are these social networking sites becoming an important source of health information? Despite their increasing popularity, few people are using them to gather and share health information. 62% of adults have used a social networking site like MySpace and Facebook and, of those, only 15% have obtained any health information. Indeed, 32% of adults use Twitter or another service to share updates about themselves or to see updates about others (Fox, 2011).

However people are talking about health issues on Twitter. An example of this is dental patients who talk and share information. Heaivilin, Gerbert, Page and Gibbs (2011) investigated the content of 1000 Twitter posts that met search criteria relating to dental pain. After excluding ambiguous tweets, spam and repeat users, 772 tweets were analysed and frequencies calculated. Of those, 83% were primarily categorised as a general statement of dental pain, 22% as an action taken or contemplated, and 15% as describing an impact

on daily activities. Among the actions taken or contemplated, 44% reported seeing a dentist, 43% took an analgesic or antibiotic medication and 14% actively sought advice from the Twitter community.

Government manipulation of Twitter

One can only speculate on the robustness of some of the dental advice that is shared on Twitter!

But it is the absence or presence of robustness that comprises much of the risk that a user encounters when they use Twitter for information. More insidious and perhaps less obvious is the misuse of microblogging sites by governments. In Bahrain, for instance, Leavitt (2011) describes how Twitter was inundated with government propaganda in a clumsy attempt to make it a less credible information source about the protests. Another example was highlighted by the BBC's Michael Bristow (2008) who reported on the now infamous '50 Cent army' where each citizen was paid 50 cents each time they posted a pro-Party comment or tweet anywhere online.

Ultimately, this problem could be avoided. The main advantage of Twitter is that it cuts out organised information dissemination and allows people to access sources directly. In the Bahraini examples, Twitter users saw through the government propaganda and in the Japanese example, social media gave the public direct access to doctors.

Biomedical conflicts of interest

Is it safe to assume that both social media and the Internet has dispensed with the need for biomedical journalists? Let's hope not because otherwise the important checks balances and scrutiny of our health systems will be lost. What patient wants direct access to a doctor if that access means that you don't know whether your doctor is prescribing you a medicine because it will help you or because he or she is being paid to promote that drug by a pharmaceutical company?

New ways must be found of delivering this democratic role and that exact problem is being addressed by the US investigative website Pro-Publica which aims to conduct 'Journalism in the

public interest' in the United States. The recent report *Dollars for Docs How Industry Dollars Reach Your Doctors* by journalists Dan Nguyen, Charles Ornstein, and Tracy Weber exemplifies some of the best biomedical reporting on the Internet. This then is the traditional and critical role of the fourth estate (Nguyen, Ornstein and Weber, 2011).

Under US law, a doctor does not need to disclose an interest in the pharmaceutical company that produces a drug the doctor is prescribing. Investigations involved the reporting, creation and publication of a database of payments made by these companies to doctors for research, speaking and consultancy.

Today's health world is filled with conflicts of interest and biomedical journalists are needed to uncover these and to report them, especially when they could potentially harm people. This job of the biomedical journalist has not been helped by what can only be described as the big cultural change we've seen towards institutions and organisations producing their own news.

Trench (2008) describes this phenomena: «Institutions have adopted a public communication model, that of journalism, in the distribution of information. 'News', or some close equivalent, is a standard feature on websites generally and many scientific institutions have adopted a journalism style of presentation to disseminate information about new developments».

Recycled news?

This presents a real challenge to independent biomedical journalism leading to lazy journalism or 'churnalism' a term used by Nick Davies in his book *Flat Earth News* (Davies, 2008). He commissioned research for the book from Cardiff University and their analysis showed that 60% of the content of UK papers was based mainly on news agency or press releases, while only 12% are original stories and only 12% of stories showed evidence that the central statement had been corroborated (Franklin, Lewis, Mosdell, Thomas, Williams and Cardiff, 2006).

Lewis et al.'s study (2008) of 2,207 newsprint items and 402 broadcasts, found that 19% of press stories and 17% of broadcasts were entirely or mainly reproduced PR material. 49% of press stories were either entirely or mainly dependent on news wire agency copy, much of which itself has come from press releases. Nearly one-third of the Telegraph stories originated in other media.

This lack of digging for original stories and the inevitable recycling of stories is further compounded by generational differences in the way in which journalists find stories. Some recent research in Germany found that found that the younger journalists were twice as likely as their older colleagues to use other media as the major source for story ideas (Reinemann, 2004).

There is the possibility that this could lead to growing inaccuracies by a process of journalistic 'Chinese whispers'. This is refuted by PR companies who argue that journalistic accuracy is increased by their sources directly being used as their quotes are direct from the source. Either way it is important that journalists return to their primary function: reporting in the public interest. This includes investigation, using primary sources, which they have verified, interviews with a large range of commentators and delivering a unique, balanced and independent news.

At its worst, it can also lead to the contamination of editorial independence by commercial interests. For example, a great deal of health information available online is provided by medical companies. Josephine, the administrator of the patient group BoneSmart, is acutely aware of this: «manufacturer's websites that always make their products sound superb with snippets of information that are either out of context, applicable to almost every other device on the market or just downright misleading! In this respect, the Internet is a very dangerous place for patients, especially where they hit upon websites and articles with information that is grossly out of date. In this, a site like BoneSmart, that has a mandate of high standards, can properly inform and advise» (St Louis, 2011).

The perils of social media?

A recent study in the US reported by (Greene, Choudhry, Kilabuk and Shrank, 2010) looked at

the Facebook wall posts from fifteen of the largest diabetes communities. They found, "approximately 27% of posts featured some type of promotional activity, generally presented as testimonials advertising non-Food and Drug Administration (FDA) approved, 'natural' products". However it's not just Facebook that can be hijacked, Twitter is also vulnerable to "fringe beliefs and scientifically unsound information" (Szomszor, Kostkova and St Louis 2011).

One of the findings of this research paper was that one of the most popular articles tweeted around the time of the pandemic was by Dr. Joseph Mercola, a American entrepreneur who edits the extremely popular alternative-medicine website, mercola.com. He has 1.6 m newsletter subscribers, millions of website hits per day and over 300,000 webpages. Dr. Mercola allegedly makes unsubstantiated scientific claims about alternative medicine, and the FDA in the US has warned him.

Another peril of social media, perhaps related to Mercola, is claims of inaccuracy or confusion. In Szomszor, Kostkova and St Louis's research they found that the most popular article tweeted about swine flu was from the satirical site, *The Onion*. The actual article was about how Republicans endorsed swine flu just to score political points against President Obama.

At the time of the pandemic, did the international readers, understand the nuances of satire? Incidentally, none of the 10 most tweeted articles were hosted by a primary source such as who. int. Perhaps more comfortingly, the study found that legacy news sources CNN, Reuters and the BBC were the first to tweet about the World Health Organisation (WHO) 'pandemic' status once declared, up to 5 hours before the WHO! It seems that the reporters with legacy news sources are still firmly on the ball with regard to news, helping to ensure a level of accuracy especially with many online-only sources such as blogs.

In fact the Pew Project found that 99% of the stories linked to in blogs came from legacy outlets such as newspapers and broadcast networks. And just four –the BBC, CNN, the New York Times and the Washington Post– accounted for 80% of all those links (Excellence in Journalism, 2010).

Do questions of accuracy lead to those of uncertainty?

As increasing access to information on the Web and other outlets allows individuals to range beyond their local media, readers will be able to assemble meaning on a grander scale by cobbling together stories about the same topic from a variety of places. It seems almost inevitable that such triangulation will make uncertainty a common take home message (Dunwoody, 1999).

So is uncertainty a given? If you access news via journalists, it shouldn't have to be. Trench (2007) considered that uncertainty is a given unavoidable condition of science in public. However, he questions whether the modern audiences can cope with this. What's needed is a shift in the way that science and medicine is understood not as a certainty but more sceptically. This shift will then allow for a contemporary model that will understand that the science of the most interest to the public is inherently uncertain. Then science-interested publics and citizens in general will be capable and willing to acknowledge and handle such uncertainty.

Conclusions

So it's no surprise that, for biomedical journalism, the Internet contains as many challenges as opportunities. However, from the patient's perspective, it has opened up new ways of accessing and consuming information enabling forum administrators to take on roles previously held by medical professionals and journalists.

But we must not allow the Internet to bamboozle us. No matter the platform used by biomedical journalists, established journalistic principles should be relied upon, rather than rejected in favour of the ease with which a journalist can consume and broadcast information. This means a commitment by biomedical journalist to investigating, challenging and disclosing more than ever before. ProPublica's Dollars for Docs exposé is an inspiring example of this dedication in action.

Journalists have always let the public know what is happening. The public can now find out a lot of things themselves and but there's always something that they won't find and that's where

the journalist steps in. Biomedical journalism is not just about being an information conduit or presenting an over optimistic stream of novel findings and treatments. In an age of online information overload the job of the journalist becomes even more necessary. Perhaps the greatest current challenge is who will fund this journalism? In order to find new funding streams, we need to find a financial model that works.

Acknowledgements

Thank you to Adam Smith for his invaluable research and for interviewing Jacqueline (surname withheld) from BoneSmart (2011) Interview with Adam Smith, as part of this research project (St Louis, 2011, private communication).

References

- Agostini A. Journalism and the challenge of the Internet, Le Monde diplomatique [Online]. 1997. [Accessed 17 March 2012] Available at: http://mondediplo.com/1997/10/internet
- Brain Talk Communities. BrainTalk Communities: Online Patient Support Groups for Neurology [Online]. 2012. [Accessed 5 March 2012] Available at: http://www.braintalkcommunities.org/
- Bristow M. China's internet 'spin doctors'. BBC News [Online]. 2008. [Accessed 17 March 2012] Available at: http://news.bbc.co.uk/1/hi/7783640.stm
- Crocco AG, Villasis-Keever M, Jadad AR. Analysis of cases of harm associated with use of health information on the Internet. JAMA. 2002;287:2869-71 [Online].
 2002. [Accessed 17 March 2012] Available at: http:// jama.ama-assn.org/content/287/21/2869.full.pdf+html
- Davies N. Flat earth news: an award-winning reporter exposes falsehood, distortion and propaganda in the global media. London: Chatto & Windus; 2008.
- Excellence in journalism. How blogs and social media agendas relate and differ from the traditional press.
 Pew Research Center Project [Online]. 2010. [Accessed 17 March 2012] Available at: http://pewresearch.org/ pubs/1602/new-media-review-differences-from-traditional-press
- Foundation for the Advancement in Research in Medicine. BoneSmart: global consumer awareness of joint replacement options [Online]. (No date) [Accessed 5 March 2012] Available at: http://bonesmart.org/
- Fox S. The social life of health information. PewInternet. org [Online]. 2011. [Accessed 17 March 2012] Available at: http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Info.aspx
- Franklin B, Lewis J, Mosdell N, Thomas J, Williams, A. The independence and quality of UK journalism. Cardiff

- School of Journalism, Media and Cultural Studies [Online]. 2006. [Accessed 17 March 2012] Available at: http://www.cardiff.ac.uk/jomec/research/researchgroups/journalismstudies/fundedprojects/qualitypress.html
- Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med. 2011;26:287-92. [Accessed 17 March 2012] Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC3043192/?tool=pubmed
- Greenfield R. The ethics of fake Twitter accounts.
 TheAtlanticWire.com [Online]. 2011. [Accessed 17 March 2012] Available at: http://www.theatlanticwire.com/technology/2012/02/learning-cormac-mccarthy-twitter-hoax/48147/
- Habibzadeh F. Evidence-based journalism [Online].
 2005. [Accessed 25 February 2012] Available at: www. ease.org.uk/artman2/uploads/1/for_the_EASE_site-essay-2.pdf
- Heaivilin N, Gerbert B, Page JE, Gibbs JL. Public health surveillance of dental pain via Twitter. JDR. 2011;90: 1047-51.
- Hinnant A, Len-Ríos ME. Tacit understandings of health literacy: interview and survey research with health journalists. Science Communication. 2009;31:84-115.
- Hoch D, Ferguson T. What I've learned from E-patients.
 PLoS Med. 2005;2:e206 [Online]. [Accessed 17 March 2012] Available at: http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.0020206
- Lacroix EM. How consumers are gathering information from Medline Plus. Science Communication 2001;22: 283-91.
- Leavitt N. The Arab World and Revolution 2.0. iMedia-Connection.com [Online]. 2011. [Accessed 17 March 2012] Available at: http://blogs.imediaconnection.com/ blog/2011/02/28/the-arab-world-and-revolution-2-0/
- Lewis J, Williams A, Franklin B. A compromised fourth estate? UK news journalism, public relations and news sources. Journalism Studies. 2008;9:1-20.
- Nelkin D. Selling science: how the press covers science and technology. New York: W.H. Freeman and Company; 1995.
- Nguyen D, Ornstein C, Weber T. Dollars for docs: how industry dollars reach your doctors. ProPublica: Journalism in the Public Interest [Online]. 2011. [Accessed 17 March 2012] Available at: http://projects.propublica. org/docdollars/
- Szomszor M, Kostkova P, St Louis C. Twitter informatics: tracking and understanding, public reaction during the 2009 swine flu pandemic. IEEE/WIC/ACM International Conference on Web Intelligence; August 2011. [Conference presentation]
- Tamura Y, Fukuda K. Earthquake in Japan. Lancet. 2011;377:1652.
- Trench B. How the Internet changed science journalism.
 In: Bauer MW, Bucchi M, editors. Journalism, science and society: science communication between news and public relations. London and NY: Routledge; 2007.
 p. 133-42.

- Trench B. Internet: turning science communication inside-out. In: Bucchi M, Trench B, editors. Handbook of public communication of science and technology. London and NY: Routledge; 2008. p. 185-98. [Accessed 17 March 2012] Available at: http://doras.dcu.ie/14807/
- US National Library of Medicine, National Institutes of Health. Medline®/PubMed® Resources Guide [Online].
 2012. [Accessed 4 March 2012] Available at: http://www.nlm.nih.gov/bsd/pmresources.html