The Pharmaceutical Mafia

A study of publics, experts, expectations, information and control.

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Abstract

Does the Pharmaceutical industry take advantage of the death of the expert and creation of issues to control the formation of publics for their own means and for financial reasons? This essay reviews relevant papers and thinking and demonstrates the power of design tactics in the creation of publics with pharmaceutical tools, such as Direct-to-Consumer pharmaceuticals and the decline in the trust of the expert and the imbalance in power. From this the report then goes on to suggest different routes to try and create balance, understanding and debate with speculative/critical and constructivist theory.

Introduction

"The Pharmaceutical mafia" is a somewhat controversial and provocative title, however one I feel is relevant to this work where I explore whether pharmaceutical companies have used their status as experts and influencers to control the creation of publics and taken advantage of the uncertainly surrounding the current mistrust of the expert. The decline in trust of experts in the world of science has been well documented including a report published by the House of Lords (2000) where they state: "public confidence in scientific advice to Government has been rocked by a series of events, culminating in the BSE fiasco" (1.1). This report was expanded upon by Wynne (2006) where he notes a "continuing failure of scientific and policy institutions to place their own science-policy institutional culture into the frame of dialogue" (1) which he considers to a be a contributing factor to the cause of public mistrust. This deterioration in the belief of the expert has been described as "a Google-fuelled, Wikipedia-based, blog-sodden collapse of any division between professionals and laymen, students and teachers, knowers and wonderers – in other words, between those of any achievement in an area and those with none at all" Nichols (2014). Although this doesn't imply that knowledge itself is gone, it calls into question how people who wield this knowledge will be recognised in the future. This creates a void in the current expert-layperson relationship that can lead to mistrust, which could in turn create the following scenario: if we do not recognise, we do not trust, if we do not trust, we do not listen and if we do not listen we do not recognise. Change can be good and the ivory towers of the expert may, in time, benefit from the siege of the mistrusting layperson, however, it is the goings on amongst the heat and dust clouds of this battle that I am interested in and the scope of this report begins to study. This report attempts to consider if pharmaceutical companies are using the confusion of this battle to enact and establish their own systems for the creation of publics, information and control, much like a mafia or syndicate establish themselves in times of confusion and crisis.

Methodology

Looking at the Pharmaceutical universe through the looking glass of a student of Actor Network Theory (ANT), Science Technology Studies (STS) and Cosmopolitics, it is apparent that the universe is extensive and, in keeping with the analogy, bigger than what has been observed. The writing detailing this universe encroaches on the infinite. Ergo, focus is required and initially is placed on the availability of information to the patient and how it is perceived. This is set to the backdrop of the Sociology of Expectations in order to analyse how the publics of illness and disease are informing themselves, the expectations this creates and whether this nurtures a disparity between expectations and reality. This is followed by a brief study of a singular relation between two human actors, the physician/doctor and the patient, similar to Wynne's (1985) description of the expert and the layperson or "doctor-patient or expert-lay" (Brown and Webster, 2004). This is an area that Brown and Webster raise as having a "scarcity of research exploring the ways tools and technologies are encompassed and embodied within [medical] social action and integration'" (p.24). I intend to utilise

Wynne's observations of Public Understanding of Science (PUS) to scrutinise the definitions of the layperson/local expert in the context of medicine and pharmaceuticals with particular focus on how or when they become an expert. This will lead finally to a consideration of whether Stenger's (2005) "Idiot" could be used as an approach to consider new research and systems. The report then goes on to suggest a number of different approaches that could be used to improve experiences, spark discussion and support education.

Fabricated expectations and designed publics

Can you create a public of your own design for your own benefit? Carl DiSalvo (2009) builds on the teachings of John Dewey's (1927) work on publics to suggest how design strategies/tactics or "designerly means" can be used to construct specific publics. DiSalvo states the following in the section "The Constructed Public and Its Problems".

> Publics are constructed in the sense that they are brought together through and around issues. But the issues themselves do not exhibit the agency to assemble people. Rather, it is the actions and effects of others communicating issues and their consequences, that prompt a public to come into being. (p.51)

And then goes on to suggest in "Identifying Design Tactics".

> Design tactics are designerly means directed towards the construction of publics. Tactics, in this case, references the work of de Certeau and his discussion of tactics and strategies in *The Practice of Everyday Life*. To de Certeau, strategies are expressions and structures of power exerted by institutions (broadly construed) that attempt to prescribe behaviour and courses of action. In contrast, tactics are means developed by people to circumvent or negotiate strategies towards their own objectives and desires. (p.52)

This demonstrates the potential to fabricate a public with design, whether it is with the creation of an issue or the design of the communication of the issue. What is particularly interesting is the statement relating to tactics where it would be entirely possible to create a public for personal gain. Given this I am proposing an extra level of intricacy that could be interwoven with DiSalvo's work, a consideration of the sociological expectational impact a fabricated issue or public has if the objectives and desires that it brought into being are simply for financial/marketing gain. I am drawing my understanding of the sociology of expectations from papers by Borup et al. (2006) and Wilkie and Michael (2009). Borup et al. state "While expectations in their general form can be defined as the state of looking forward (from Latin, exspectatio, looking, waiting for), technological expectations can more specifically be described as real-time representations of future technological situations and capabilities" (p.286) and they also demonstrate the concept of the "hype cycle". In the case of pharmaceuticals, Direct-to-Consumer (DTC) pharmaceuticals and self-medication are what I believe are key sources of expectations. It is clear to see the publics and expectations that DTC advertising can create. Using the "hype cycle" as a reference I give the following example: If an expensive drug is promoted through DTC as being designed to treat "lung cancer" (technology trigger) and all an individual would have to do is "ask their physician" it seems likely they would either enquire or perhaps demand the medication, expecting it to treat them or even cure them (peak of expectations). However, DTC did not explain that the drug should only be taken after a series of other procedures or hasn't been tested at a certain stage of the illness. This is where, I think, the mistrust of the expert and the lack of time/desire for an expert to discuss with the public/patient causes the issue. Theoretically the discussion or education about the technology/drug would lead to an event similar to "the trough of disillusionment" allowing the technology to eventually become productive when it is understood and correctly used. However due to a lack of education, or the means to educate oneself correctly, the decline of expectation, which could lead to a larger discussion about other options, never occurs. This entire process and the impact

attached to it is rendered ostensibly more complicated with the availability of self-diagnosing and self-medication environments. Research by Balance Activ (2012) demonstrated that two out of three participants misdiagnosed themselves and a quarter bought the wrong medication after the misdiagnosis. Furthermore, 45% of the participants, having diagnosed themselves online and sought "high street treatment", never check with a pharmacist or counter staff if they are buying the correct medication. The research also demonstrates that the participants would consult the internet over friends, families and doctors if they felt the issue was "embarrassing" (50%). This in turn presents another Pandora's box of issues about normalisation of ailments and people not feeling comfortable about talking to one another about medical issues leading them to console and confide in the internet. I am however, going to leave this particular box shut for the scope of this essay. Secondly, recently WebMD (2010), a global self-diagnosis website, was criticised for having a depression questionnaire where all answers, including consistently answering "no", diagnoses: "you may be at risk for major depression". Additionally, the site then recommended the use of a drug called "Cymbalta" that is sold by one if WebMD's sponsors, Eli Lilly. This lead US Senator Charles Grassley to demand an investigation into the link between WebMD and Eli Lilly and claimed that "people may rely on the test, thinking it is objective when in fact it's sponsored fluff". These examples demonstrate the possibility for individuals to inform themselves incorrectly and the opportunity for pharmaceutical companies to create designed publics with fabricated expectations. This in turn can lead to a separation in understanding and expectation as well as profound schism between the doctor and patient. The next section of this essay focuses on the logical progression of this, the layperson becoming a self-proclaimed expert and the implications of that.

Becoming an expert, a question of definition.

When does an expert become and expert? Wynne's (1985) study of Cumbrian sheep farms after the fallout of the Chernobyl Nuclear disaster demonstrated not only the importance of the public trust in the expert but the expert's need to understand the importance of public or local knowledge. This is further reinforced by a recent paper by Hendriks et al. (2015), which details the three necessary dimensions for an expert to be trustworthy; expertise, integrity and benevolence. These highlight part of the reasons for mistrust and therefore the need for the "layperson's" expertise; if you can't trust the expert, you yourself must become one. However, as before, "when does an expert become an expert?". What I am really asking is when does any individual have enough knowledge/experience/education to be deemed an expert? By definition, an expert is: "highly practised and skilful, or well informed, in subject", the use of the word "well" is what I think is important here. Simply being "informed" isn't enough; rigidity, quality and true understanding are more important than "I read it in an article", or worse. The ubiquity of the internet has seen a rise in the access to information for all. However, the validity of some the information, or lack thereof, has recently been strongly called into question with many enquires and researches into false news and information, for example the recent work of Shao et al. (2016). However, correct information can still be mis-sold and misunderstood. An extensive report by Laing et al. (2010) details the perks and pit falls of this new source of information amongst other elements. What I think is one of the true issues with the new emerging expert is the difference between an "informed" and an "educated" expert. This isn't bringing into question the importance of access to information, but the importance for experts to have an appreciation for the limits of their experience and knowledge. For example, a cancer specialist physician understands a wide variety cancers including the sub-category of each and which drugs are appropriate for each, however this is a broad knowledge with a specific experience. On the other hand, a patient has a single cancer and can learn every detail about clinical trials and available drugs, has the experience of living with the disease and may disagree with the physician's opinion but may not have the time or resource to fully understand the intricate implications of how different drugs work. This would historically cause an impasse accentuated by a traditional expert

tending to ignore the input of the local expert. This is until you factor in the newly available bypasses like DTC. A report by Williams et al. (2011) that details a number of social implications and influences of "pharmaceuticalisation" states: "Another important vehicle for pharmaceutical market expansion is direct-to-consumer (DTC) advertising. To date this is limited to countries such as the USA and New Zealand, although attempts to overturn the ban, or at least to change the rules to enable pharmaceutical companies to provide more 'information' to patients, continue in Europe." (p.713) and "along with a range of other ways of marketing disorders as well as drugs, including what Angell (2005) appositely dubs 'marketing masquerading as education' and 'marketing masquerading as research'" (p.713). This demonstrates the desire to create a "false expert" that will try to influence an expert's opinion based on incomplete knowledge for the purpose of improving sales over medical reasoning. A report of public and physician response to DTC (Robinson et al., 2004) shows that physicians consider DTC as misleading in terms of cost (98.7%) and alternative treatment options (94.9%) and that DTC changes the patient's expectations of physicians' prescribing practices (67%). The report also covers public opinion, showing that only 29% found DTC to be a positive trend of healthcare which could indicate that DTC isn't having the desired impact. However, though the coverage of experts was extensive, I consider the coverage of the public, albeit quantitative at 500 individuals, to be too general for this topic. It would have been better to ask people who are suffering from illness what their opinion of DTC was as they have a greater investment into the potential for new treatments for their conditions. Looking once again at self-diagnosis, a paper by Semigran et al. (2016) demonstrates the inaccuracies of self-diagnosing algorithms (or symptom checkers) compared to physicians when provided with the same information (in this case, the patients' medical histories). The study shows that physicians were 72% accurate with their first diagnosis and 84% accurate with their top three possibilities, whereas apps were 34% and 51% respectively. The report does conclude that, whilst within estimated levels of error, the physician accuracy could be higher and goes on to suggest that the algorithms themselves could help to fill the gap. This section details how there is a dogma forming around the self-fulfilling prophecy of the false expert and how current experts are fearful of the teaching of this new belief. Furthermore, although I asked the question "when does an expert become an expert?", I failed to answer it. I believe this is due to a need for further research and design leading to a definition. However, we cannot, nor should we, return to the relationship of before. In the section that follows, I will begin to consider what different avenues of designs and research could be used to tackle issues and engage the publics.

Accepting the future, deploying designers and fighting fire with fire.

So, what can be done? The solution is not to just "trust them, they are doctors", we must create an environment through design that allows education and understanding. In an interesting symmetry in media and journalism a similar re-evaluation of an old debate is underway. The debate is described by Allan (2009) as the "Lipmann-Dewey debate". Walter Lipmann, an American writer and reporter, believed that the news and related writing should be crafted by professional, elite, trained journalists as the general public are uninterested or unfit to perform the task. Whereas, John Dewey, a philosopher of pragmatism, believed it is quite to the contrary and states that journalism requires public involvement and uptake moving forward. I have demonstrated a number of ways physicians, doctors and other traditional experts are not satisfied with quality or accuracy of the information currently available. However, simply stating that it is wrong and expecting everything to go back to what it was. For this I consider two strategies, firstly the approach described by Michael (2012) which takes the concept of the idiot as a process that aims to "problematize and rethink the ideal typical distinctions that have been drawn between designerly and social scientific versions of public engagement" (p.544). With this, designers and social scientist can delve further into research around Public Engagement with Science (PES), Public Engagement with Pharmaceuticals (PEP) and the associated (and likely, currently ignored) misbehaviours, and create bodies of work that could be

speculative/critical to the degree of being functionally useless but evoke questions/debate around pharmaceuticals such as the work of Hopfengärtner's and Zeller's project "Life is Good for Now" and Kolkman's project "OpenSurgery" which can lead to larger bodies of work such as "Material Beliefs" (Beaver et al.,2009). Secondly, to take a more pragmatic approach, I turn to the considerations of constructivism where it is important to "call on prior knowledge and experience when developing instruction" (Duffy et al., 2013) In this regard, one solution might be to develop a site or sites that are in a similar vein to that of the WebMD's of the world but are such that they are certified and regulated by experts and perhaps even government funded to remove the possibility of conflict of interest. An example of this could be the British solution, NHS Choice but slightly remastered so it became more user friendly. Another option, would to create an alternative qualification/recognition that allows a well-informed layperson to become an "expert" or, essentially, qualified to treat themselves to a certain level.

Conclusion

One day our bodies will diagnose themselves and tell us what is wrong. Until then it is important to try to understand the intricacies and complexity of the human body, pharmaceuticals and science or at least appreciate them. This report has demonstrated how the pharmaceutical industry can use its position, the unbalance and changing definition of the expert-lay relationship and designerly means to create publics, expectations and dynamics of their own design and for their own benefit. Current experts, designers and social scientists must work together to ensure the next generation of experts are well informed and correctly educated. Taking inspiration from Stenger's (2005) and Michael's (2012) respective works, it would be interesting to further study and consider PEP as a subsection of the PES and whether different formats of design could be employed to create different events and engagements with the publics. Whilst I admitted at the start that I would be unable to cover all of the cosmopolitical elements of the pharmaceutical universe, there are a number of elements I would study were I to have more space or write another essay. First of all, I would have liked to analyse, in a similar factor, other actors (such as policy makers and laboratory scientist) with consideration towards Latour's "Versions of Political". On top of that, it would be a rich and beneficial endeavour to study the gender politics of pharmaceuticals whilst taking a leaf from feminist scholars such as Haraway (whom of which I saw mentioned in a number of related articles). Finally, whilst I put forward a variety of approaches that could lead to improve education of publics and speculative/critical discussions on pharmaceuticals, I recognise that I am plagued by Latour's conundrum of "everything is political", If everyone is an expert, no one is an expert. If we assume that the education I discuss does occur and given the nature and diverse approaches of science, everyone being an expert could result in a never-ending debate of the correct avenue to take.

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