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Sub Theme: Being Good or Looking Good

Title: Bittersweet charity: an investigation into the relationship between big pharma, antidepressants and mental health charities in the UK

Introduction:

When a corporation experiences scandal or a loss of reputation, corporate social responsibility (CSR) in the form of donating to charities can offer welcome relief. By donating, corporations can improve their reputation with stakeholders. This practice has been criticised as being less than ethical, and more a demonstration of enlightened self-interest or image-washing than as evidence of true moral responsibility. This issue becomes even more complex when considering the relationship between pharmaceutical companies and charities. Pharmaceutical companies have been at the centre of numerous scandals over the past two decades. Like other organisations, they now collaborate with charities to improve their image. However, the conflict of interest which exists between charities who provide services and impartial information for people with depression, and antidepressant manufacturers who need to generate profits for shareholders muddy the waters considerably.

This paper explores the relationship between mental health charities and pharmaceutical companies in the UK. Ultimately concluding that, whilst historically antidepressant manufactures have used charities to promote their marketing messages, they now invest in charities with the enlightened self-interest of improving their reputation.

Background:

In the late 80s and early 1990s the antidepressant market exploded with the introduction of selective serotonin reuptake inhibitors (SSRIs). These drugs, of which Prozac is the most notable, were considered 'blockbuster drugs' (Buckley 2004, p. 6) by psychiatrists. Between 2000 and 2005 alone prescriptions for SSRIs rose 45% (Moore et al 2009). However, the meteoric rise of SSRIs has since been subject to great criticism.

In the decades since their launch SSRIs have been at the centre of numerous scandals. Due to the complex nature of the brain, we have never know how antidepressants really work. More recently researchers are questioning whether the drugs even work at all. A clinical trial funded by GlaxoSmithKline (GSK) investigated the use of their antidepressant paroxetine (brand names: Seroxat/Paxil) in adolescents. The original paper publishing the initial results of the study, referred to as Study 329, found that 'Paroxetine demonstrated significantly greater improvement compared with placebo' and that it was generally well tolerated in patients (Keller et al. 2001, p. 762). However, after

a decade long quest to obtain and analyse the original trial data Keller et al.'s (2001) findings were disputed. Le Noury et al (2015) found that instead, the data showed that paroxetine was not statistically or clinically significantly more effective than placebo. When looking at the tolerability of the drug the Le Noury et al. found that the original publication had analysed the data in a way which masked the severity of side effects (self-harm, suicidal ideation and attempted suicide were referred to as 'emotional lability'). The reanalysis of Study 329 has been reported widely in the media, further undermining public confidence in antidepressant manufacturers.

Perhaps most controversially SSRIs have been linked to homicide (Healy et. Al 2006). Notable psychiatrist and industry commentator David Healy has served as an expert witness in several murder trials where the defendant has killed someone shortly after starting or changing an antidepressant medication.

The soup of controversies surrounding SSRIs, in addition to limited understanding of the brain, has caused most large manufacturers such as GSK to exit the antidepressant market. The small number of drugs which have been launched in recent years have faced an uphill struggle for acceptance. When other antidepressants have been accused of being at best better than sugar pills, and at worst turning people into murderers, how can manufacturers create legitimacy for new drugs? Enter charities.

Whether charities should receive donations from pharmaceutical companies is a contentious subject. Leading UK mental health charity Mind refuse donations from pharmaceutical companies and depression device companies due to the perceived conflict of interest (Mind 2017). However, many charities continue to receive these donations, often to fund awareness campaigns.

Charities are often involved in activities to increase awareness of the condition they represent. Disease awareness campaigns are the pinnacle of this activity and represent a high-profile effort to increase understanding of a condition. The first depression awareness campaign in the UK was the Defeat Depression Campaign (DDC). DDC ran from 1992-1996 and received significant funds from antidepressant manufacturers which critics argue undermined the messages of the campaign (Healy 2004; Moncrieff et al. 2005). Prozac manufacturer Eli Lilly funded the campaign along with GlaxoSmithKline (then SmithKlineBeacham). Both organisations would benefit from increased awareness of depression and its treatments, so their funding of the campaign aligned with their business interests. However, Moynihan and Henry (2006) argue that disease awareness campaigns funded by pharmaceutical companies go beyond informing a latent 'sick' community of the treatment options available to them. Instead, propelled by the interests of funders, these campaigns ultimately convince healthy people that they are ill and need treatment. Such campaigns can therefore serve to generate market demand for drugs. This phenomenon is known as medicalization or pharmaceuticalization (Abraham 2009, 2010). Medicalization refers to 'a process by which nonmedical problems become define and treated as medical problems' (Conrad 1992, p. 209).

Medicalization an innocuous term, and is not always an indication of malintent. Abraham therefore coined the term pharmaceuticalization to better capture the motives of pharmaceutical companies which he believes influence the overmedicalization of conditions. Industry funded disease awareness campaigns are theorised to contribute to pharmaceuticalization via disease mongering. Disease mongering refers to 'the selling of sickness that widens the boundaries of illness and grows the markets for those who sell and deliver treatments' (Moynihan and Henry 2006).

This paper explores the recent relationship between pharmaceutical companies and charities. The primary aim being to understand whether pharmaceutical companies are funding charities out of a genuine desire to be ethical, disease monger or, as is often the case with corporate donations by big pharma companies, to improve reputation (image wash).

Methods:

The data drawn upon in this paper is part of a larger piece of research undertaken for a PhD. The methods included the following issues:

1. Investigative social science

The activities of pharmaceutical companies have been characterised as lacking in transparency across the board (e.g. Goldacre 2015). The reanalysis of Study 329 data mentioned earlier took a decade due to issues with transparency and access. Not wishing for my PhD to last a decade, once access was denied from several pharmaceutical companies I turned to an alternative methodology that relied less on formal access. The approach I adopted is referred to as investigative social science. The approach incorporates aspects of investigative journalism. My own mix of investigative social science was predominantly inspired by journalist Mark Lee Hunter who uses an investigative approach to write organisational case studies without access (Hunter 2011). This interdisciplinary approach is novel in business management research. However, versions of it have been used by sociologists for decades (Douglas 1976; Levine 1980; Ho et al. 2006).

2. Data collected

a. Documents

A broad range of documentary evidence has been collected.. Documents from DAWa run by Depression Alliance and sponsored by various pharmaceutical manufacturers have been electronically obtained. Furthermore, using Freedom of Information act requests the historic financial accounts of Depression Alliance have been accessed. Additionally, media coverage of the charities work has been obtained via digital newspaper archives.

b. Interviews

The documentary evidence has been supplemented by 45 interviews taking place between June 2015 and December 2016. Interviews were recorded and transcribed in accordance with the ethical approval obtained for the research. I selected respondents based on the specialist knowledge and information they were likely to have, inspired by the investigative approach of Abraham et al (2009). Abraham refers to interview participants as informants because of the specialist knowledge they are sought out for. Therefore, in this paper interview participants will henceforth be referred to as informants. Interviews took place with informants from the following stakeholder groups:

Pharmaceutical industry employees

7 interviews took place with pharmaceutical employees such as sales representatives and marketing managers. These informants spanned many companies and will not be linked to their respective organisations in any discussion of findings.

Healthcare Professionals

General practitioners, psychiatrists, pharmacists and mental health nurses comprise this category of informants. 6 of these informants were selected specifically for their financial links to pharmaceutical companies. The ABPI disclosure list contains information on healthcare professionals who received money from pharmaceutical companies in 2015 and chose to be transparent about the transaction (ABPI 2017). Most of these healthcare professionals did consultancy work for pharmaceutical companies, some of which included liaising with charities or advising on marketing messages.

Medical Public Relations (PR) employees

Medical PR agencies play a key role in the marketing of pharmaceuticals, particularly in the launch of new products. Traditionally PR agencies liaise with the press to protect, enhance or build their reputation. Brezis (2008, p. 86) suggests that public relations agencies can play in important role in the phenomena of disease mongering.

Charities

Charities produce information documents, run disease awareness campaigns, and more generally provide a key source of information for patients and the public. Within the depression/mental health cohort of charities there is a split between organisations who do receive pharmaceutical funding and those who refuse such donations.

Industry Commentators

The ethical status of the pharmaceutical industry is a contentious subject which subsequently provokes lively public debate. A growing body of literature exists of journalistic books commentating of the activities of the pharmaceutical industry. Whilst the authors of these books are professionals whose career is intertwined with their views, there also exists a community of more casual commentators.

Findings and Analysis

Antidepressant manufacturers have retained links with depression charities in the UK. Most notably, antidepressant manufacturers have funded aspects of some depression awareness weeks (DAW) in recent years. Manufacturers reasons for engaging with charities is multifaceted and is conceived of differently by different groups of informants.

One pharmaceutical sales representative that was interviewed highlighted a move away from disease mongering in recent years:

...obviously, every company is not a charity, every company has to generate profits to their shareholders and more importantly have the funds to continue investment into research and development, bring the drugs to market and that's a massive cost. So absolutely, companies are driven by generating profit. But, because we are such a regulated industry the main thing is that medicines are used in the right patients. So, a lot of the conversations over the years I've spent having are, whether it be policy makers, budget holders or clinicians etc. are, you need to get this medication right, in the right patients because the last thing you want is it being used over here in the wrong group of patients. Particularly say in mental health because the patient is going to have a bad experience, the clinician is going to have a bad experience, and then, potentially, everyone's going to say oh that medicine doesn't work, but they're not going to know that it didn't work because it was used in the wrong patient (*Fieldwork interview*, 18/06/2016)

In the wake of scandal, companies want to avoid their medications being used in the wrong patients. If a medication is prescribed to someone for whom it is not necessary, they are likely to have a benign or negative reaction and the prescriber will have a bad experience prescribing the drug. Even worse, if the individual has an extremely bad reaction as is documented in the recent publication *The Pill That Steals Lives* (Blackford Newman 2016), public opinion of the drug and the company may deteriorate.

This risk averse, reputation preserving sentiment is also reflected in DAW. DAW takes place every year in April and has frequently been partially funded by pharmaceutical companies. Depression

Alliance (DA) are the largest depression specific charity in the UK and so organise most of the week's events.

In 2005 DA received funds from Eli Lilly who had recently released duloxetine (Cymbalta). The antidepressant also treated psychosomatic pain. This year a message which appeared throughout the week (but not other depression awareness week) was the prevalence of psychosomatic pain in depression. In 2008 Depression Awareness Week was part funded by French company Servier and the PR company they hired to help promote their drug Agomelatine (Valdoxan). Agomelatine shares properties with the hormone melatonin and resultantly helps regulate sleep. In 2008 sleep was more of a focus of the campaign.

Both the 2005 and 2008 awareness weeks retain characteristics which could be perceived as contributing to Moynihan and Henry's (2006) definition of disease mongering. However, in 2015 and 2016 Depression Awareness Week was part-funded by Lundbeck. An informant from a charity which ran the week specified that Lundbeck only funded certain activities of the week. Most specifically, Work in Progress, a branch of DAW which focussed on the management of depression in the workplace (Depression Alliance 2017).

Lundbeck have released a new antidepressant called Vortioxetine (Brintellex). Vortioxetine distinguishes itself from other antidepressants by treating problems with cognition which are sometimes experienced by people with depression. As the 2016 week occurred during data collection, I had already identified the pattern of the depression awareness week funders and the content of the weeks' messages. I was therefore expecting the week to focus in part on the cognition symptom of depression however this was not the case. Instead, the activities of the week which were funded by Lundbeck were focused on the workplace management of mental health. Furthermore, regulation was consistently referenced wherever it was noted that Lundbeck provided funds for some aspects of the week.

Recent depression awareness weeks characterise a move away from the disease mongering which was more evident in the 1990s. Informants from the pharmaceutical industry described how this approach is in line with the profit motives of companies and that encouraging prescribing in the wrong patients harms the industry. This begs the question, if antidepressant manufacturers are not funding disease awareness campaigns to widen the pool of patients who can be prescribed a drug, why do they bother? Medical PR professionals outlined a more nuanced explanation for contemporary industry-charity relations.

Charities are very important in pharmaceutical communications. They allow the patients' voices to be heard illustrating the impact of the disease or condition, easing access to opinion leaders and patient case studies and in proving a credible and relevant third party perspective on your story. Charities are also vital in calling for changes in policy and in supporting the

case for access to medicines, whether that means drug approval or budget allocation. Fieldwork interview [20/12/2016]).

PR informants noted that rather than being used as distributors to promote marketing messages to the potential patients, charities are now valued for their reputation. To be approved, and make it onto the formularies of clinical commissioning groups (CCGs), manufacturers must make the case that their drug is value for money. Charities therefore add legitimacy to the condition and its treatments and, as highlighted in the quote, provide access to patient case studies which illustrate the impact of a disease on a personal level. This change of focus of industry-charity relations in the depression sector, from the public to regulators has yet to be explored in the literature and offers a rich area for future enquiry.

Conclusion:

Rather than being an example of disease mongering, as was evident to some extent in the campaigns of the 1990s, the funding of charities by antidepressant manufacturers has taken on a different purpose. Regulation has become of utmost importance and by promoting adherence to regulation manufacturers are attempting to rebuild their reputations in the wake of scandal. Instead of utilising charities to spread marketing messages, manufacturers are co-opting charities identities. This departure from disease mongering potentially reassuring, however further research needs to be done into the new targets of industry-charity relations.

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