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## From fantasy to reality: managing biomedical risk emotions in and through fictional media

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### Abstract

In this article, we explore the role that fictional media (film and television) play in evoking and managing collective and individual anxieties towards biomedical research. We draw on two data sets: fictional media depictions of human research subjects and interviews with Phase I clinical trial participants conducted in the USA in 2013. We show how fictional media provide an outlet for collective uncertainties surrounding biomedical research through depictions that mock and dehumanise research participants, using such emotions of shock, disgust, pity, amusement and humour. We analyse how themes from fictional media are also used to manage actual clinical trial participants' own anxiety concerning the unknown risks of research participation. By contrasting the reality of their research experience with fantasy derived from entertainment media, clinical trial participants minimise the seriousness of the side effects they have or may experience in actual Phase I clinical trials. We conclude that fictional media serve an important role in the collective and individual management of risk emotion.

### Keywords

risk; fictional media; emotion management; risk emotions; clinical trials; healthy volunteers

### Introduction

In this article, we examine the role that fictional media play in evoking and managing collective and individual anxieties towards biomedical research by focusing on how clinical trials are represented in film and television and how participants in Phase I trials reference such media representations. By combining these two sources of data on popular depictions of medical research, we aim to provide insight into the relationship between risks, emotion and the media. We will show how fictionalised representations of clinical trials provide a frame for managing risk emotions and how within the media themselves, comedy and horror

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manage collective anxieties about science by dehumanising research subjects and thereby removing them from the moral sphere. Within actual clinical trials, we will examine how healthy volunteers contrast reality with fantasy to assuage the risk anxieties that correspond with their voluntary participation in pharmaceutical testing. In both cases, fiction emerges as a critical foil to the actual risks of biomedical research.

## Media, risk and emotions

### Risk and emotions

While biomedical research may be seen as a positive force for advancing society through medical breakthroughs, it can also be seen as an unscrupulous enterprise that exploits individuals for the sake of advancing knowledge and/or profit. Beck (1992) has argued that in the global North a new type of social formation is evident, a risk society, in which scientific advancement creates new types of risks that elude traditional state control and regulation. Beck contended that in these societies individuals become the site of risk, wherein they are vulnerable to and experience the anxiety of this new form of risk. Recent scholarship has highlighted the role of media in shaping individuals' awareness of risks (Tulloch & Zinn, 2011). While this research provides insight into the ways in which journalistic narratives shape news media representation of risk (Mairal, 2011; Pollard, 2011; Roslyng & Eskjær, 2017), there has been limited analysis of representations of risk in fiction. Popular fictional media can serve as a mechanism for collectively confronting mixed emotions surrounding the role of biomedical science in society (Wald, 2008). This can be seen in the ways in which films like *Frankenstein* and the *Planet of the Apes* franchise articulate collective hopes and fears about the promise of science. There has to date been no analysis of the ways in which popular representations of science in general, and clinical trials specifically, inform the risk negotiations of subjects participating in clinical research.

Drug development requires the participation of humans to test the safety and efficacy of new pharmaceuticals before they can be approved for market use. Phase I clinical trials, in particular, typically recruit healthy volunteers to measure the adverse effects of these drugs. Without the possibility of medical benefit, healthy volunteers enrol in these clinical trials for the financial compensation they can receive from their participation (Abadie, 2010; Fisher, 2015), so their decision to risk being harmed from a study drug is based, at least in part, on their sense that the compensation will make taking this risk worthwhile (Cottingham & Fisher, 2016). This decision, however, can be fraught with anxiety, especially when participants are unsure about what trial participation entails.

### Fictional media and collective emotions

Researchers in medicine, the social sciences and humanities have shown that fiction is a site where broad social concerns, including concerns for potential physical harm, are articulated and can be studied. They have, for example, examined the ways in which fictional media provide inaccurate representations of science and medicine (Collee, 1999; Kirby, 2003; Manfredini, 1999) and also shape the public's understanding of and engagement with science (Bourdaa et al., 2013; Dudo et al., 2010; Stilgoe, Lock, & Wilsdon, 2014; Van Den Bulck, 2002; Van Riper, 2003). Alongside such concerns with 'factual accuracy', researchers

have also examined the ways in which fictional media produce narratives about science and medicine through, *inter alia*, the collective framings of bioethics (Chambers, 2001; Montello, 2005); broader social concerns about humanity in a changing scientific landscape (Lyntheris, 2016; Nerlich, Clarke, & Dingwall, 2001; Pethes, 2005; Wald, 2008); and the portrayal and communication of risk (Mairal, 2011; Nerlich, Clarke, & Dingwall, 2000). As Foucault (2002) has argued, texts play an active role in shaping and constructing reality, so fictional media provide more than mere representation or expression of collective concerns. They also involve a complex process of production with collective effort to create, edit, produce and broadcast film and television (Kirby, 2003). Furthermore, fictional media are collective in their consumption and incorporation into the lives of audiences – as discourse, fiction produces ‘the phenomena that it regulates and constrains’ (Butler, 2011, p. xii). Thus, fictional media expand and constrict the repertoires of meaning from which individuals can draw to make sense of the ongoing uncertainties brought about by scientific changes that Beck (1992) argues are endemic to contemporary society.

Collective concerns, anxieties and fears about potential harms have played an under-appreciated role in the translation of biomedical research into entertainment. What ‘representational’ views of fictional media tend to gloss over is that in order for such media to be entertaining, they must do more than represent these social concerns. To genuinely mirror collective anxieties would not, one would expect, be a source of entertainment. Scholars have called for more analyses of emotions as both products and producers of social life, exploring what emotions *do* rather than what they are (Ahmed, 2004; Fox, 2015). Meanwhile, risk scholars have called for increasing attention to the interrelatedness of both risk and emotion (Lupton, 2013; Zinn, 2006). The study of fictional media can increase our understanding of the role of film and television as sites for both evoking and managing risk emotions of anxiety and fear. Such analysis should highlight the ‘cultural structures’ that shape individual emotional experiences (Kusenbach & Loseke, 2013), without restricting such processes to a Freudian cathartic release (Scheff, 1979). Fictional media may evoke volatile emotions in a safe and socially sanctioned manner, but they may also provide certain repertoires for managing negative emotions in the ‘deep’ sense of modifying rather than masking authentic feelings (Hochschild, 1979). As we will show, these repertoires are strongly linked to humour and horror.

In this article, we examine biomedical research in fictional media to increase understanding of how media representations elicit risk emotions and how these emotions are managed. While past work on science and biomedicine in fictional media has examined topics such as outbreak narratives (Wald, 2008), zombie cinema (Wonser & Boyns, 2016) and considerations of Frankenstein and Dr Moreau (Kirby, 2002; O’Neill, 2006), we focus on the ways in which fictional media operate as sites where groups can vicariously experience and manage unease, anxiety and fears. In addition, we consider how *individuals* take up and use fictional media in order to minimise similar risk emotions. While emotion management scholars have primarily looked at individuals as the unit of analysis (Hochschild, 1983; Kusenbach & Loseke, 2013), in this article we bring together both collective and individual emotion management practices through a combination of media analysis with individual interviews. We aim to identify the repertoires forged in fictional media and how these repertoires are taken up by individual participants enrolled in medical research. These

methods can show how collective and individual emotion management strategies overlap to confront emerging new risks of biomedical research.

## Methods

Given our interest in the individual and collective management of risk emotions, and particularly the role of fictional media in these processes, the current study combines a content analysis of fictional media with interview data representing clinical trial participants' reflections on biomedical risk in film and television. This combination allows us to trace how biomedical research is portrayed in fictional media and how participants use this type of media to manage their feelings about the risks of participating in Phase I clinical trials. We first examine fictional representation of research using human subjects by analysing the content of a selection of films and television episodes. This enabled us to identify the ways in which fictional media framed such research and the human subjects who participated in it. We then explore the ways in which such representations and frames were evident in the reflections of individuals taking part in such research, healthy volunteers in Phase I clinical trials.

### Media representations

Our content analysis of fictional media (Altheide, 1987) was based on an analysis of a sample of film and television programmes that included representations of human participation in biomedical research between 2004 and 2014. As a result, our media sample included only fictional items that portray research subjects engaged in biomedical research, excluding those that reference biomedical science but do not explicitly show research subjects as well as items centred on psychological experiments. Following other scholars (Steinke, 2005), we used the online database IMDB.com to search for media items using terms like 'medical research', 'clinical trial', 'human subject' and 'human guinea pig'. IMDB is one of the world's largest databases archiving information about films and television shows, including content from around the world, and because of its search functions, it is considered an appropriate and useful tool for identifying media content (Wilson, 2009). To facilitate access to media content, we restricted our search to include English-language titles, which may have skewed the sample towards US productions. Roughly a third of our sample are non-US productions, including 11 Canadian, 5 British, 1 New Zealand and 1 Australian production. Our final media database included 65 films and TV dramas, depicting 157 research subjects.

We analysed the content in terms of: the genre of each media source (as classified by IMDB, such as comedy, thriller); the overall presentation of research subjects as positive, negative or mixed; and the emotions evident in these representations. Twenty-six of the media sources (40%) were classified by IMDB.com as drama, 21 as comedy (32%), 10 as thrillers/horror (15%) and 8 were classified as action or crime (12%). These source-level classifications, though, were not always applicable to the scenes in which human subjects were portrayed. Human subjects could be included in a film or TV programme generally classified as a drama but portrayed in comic or thrilling ways. Hence, in our final analysis, we took detailed notes about or discussed at length the scenes in which human subjects were

portrayed to better understand how the portrayal evoked distinct emotions. We also coded the content for demographic details on the perceived ethnicity, gender and class-background of each of the 157 human subjects. We divided up the materials to watch and code the material using a pre-established coding scheme along with sections that allowed for unexpected, emergent themes. Once these were coded independently, we cross-checked our findings with each other to resolve any questions about how to classify the data. More details on our collection and analysis of media content, as well as a full list of included media and descriptive information on these data, can be found in Fisher and Cottingham (2017).

### **Clinical trial participants**

To examine research participants' views of biomedical research and their management of risk emotions, we conducted semi-structured interviews with 178 research participants enrolled as healthy volunteers in Phase I clinical trials in the USA. Given our focus on individuals' perceptions of medical research and risk emotions, in-depth, semi-structured interviews are an appropriate method that 'opens the way to understanding how particular individuals arrive at the cognitions, emotions, and values' (Miller & Crabtree, 2004, p. 200) concerning the risks of Phase I clinical trials. These interviews were collected in 2013 as part of a larger project examining the participation of healthy volunteers in Phase I clinical trials in the USA (see Edelblute & Fisher, 2015).

Participants varied in age, gender, and ethnic and educational backgrounds and are comparable to other samples of Phase I volunteers (Fisher, 2015; Fisher & Kalbaugh, 2011). To identify and enrol healthy volunteers in the study, we visited research facilities specialising in Phase I trials. Following informed consent, participants were interviewed at the research facility where they were enrolled and were asked general questions about their educational and employment background, their reasons for enrolling in a clinical trial, their perceptions of the risks and benefits of participation, and their experiences in trials to date.

Each interview was coded in two stages by at least two different team members in order to apply the coding structure consistently and continuously interrogate assumptions and arguments as a team (Seale, 1999). Codes spanned many aspects of healthy volunteers' participation in clinical trials, including their perceptions of the risks and benefits, their decision-making about enrolment in studies and their general health behaviours. For example, when coding the multidimensional aspects of risk perceptions, we included the following subcodes: overall risk perceptions, initial risk perceptions, short-term risks, long-term risks, specific study risks, health as protective and study oversight as a risk mitigator. The main code category of 'risk perceptions' and its subcategory of 'initial risk perceptions' were of particular relevance to the data used in this article. Specifically, many examples of fictional media items emerged from participants' discussion of their initial impressions of risk, that is, their perceptions of clinical trials before ever having participated in one. These reflections were often framed as a misunderstanding about what clinical trials entailed. After the interviews were coded in their entirety, we further scrutinised excerpts that had risk perception codes to identify references to fictional media and to examine how these references were used in relation to their perception of the risks of clinical trials.

The research was approved by the Biomedical IRB at the University of North Carolina at Chapel Hill (13-1256, approved 14 March 2013). We use pseudonyms in our discussion of the interview data in order to assure the confidentiality of participants.

## Limitations

While the media and interview data are well-suited to address questions of representation and risk perceptions, they are not without limitations. The most notable limitation is the predominant focus of the media database on USA productions. While one-third of the sample is from outside the USA (Canada, the UK, Australia and New Zealand), the majority are USA productions. While this is a limitation in the sense of generalisability, it does allow for clearer consistency between the fictional media analysed and the perceptions of the USA-based participants in Phase I clinical trials who make up our sample. As a result, the findings may be limited to the USA and further research should look at these issues in other contexts.

A second limitation of this study is the use of interview methods. Our study on healthy volunteers in clinical trials did not aim to query how fictional media shaped their perceptions of clinical trials. This was a theme that emerged largely unprompted in interviews with participants. As such, not all participants in the study spoke at all about fictional media or how it might have shaped their views of medical research prior to or while participating in a clinical trial. Yet, the fact that fictional media is used as a stand in for well-formed initial impressions is itself a notable finding that we think remains worthy of scrutiny.

## Findings

### Research participants in fictional media

We identified two dominant themes in film and television representations of medical research participants. First, the depictions of research participants often served as comic relief in fictional media, regardless of the film's or show's genre. These comic plot lines centred on participants' desperation for money or general ignorance of the negative side effects that would inevitably follow. Second, some representations evoked horror and provided the vicarious experience of fear of the unknown while framing research subjects as victims. Underpinning both types of representations was the depiction of participants as deviant or inferior; for example, there were references to participants' mental illness, financial desperation or criminality, and these all served to categorise participants as somehow undeserving. Men, in particular, were depicted as inferior and emasculated subjects.

Humour was a common theme underlying the representations of human research subjects in fictional media. Roughly a third of the programmes that included human research participants were classified as comedy, and portrayals of participants even in dramas were at times intended as comic relief, giving viewers the chance to experience feelings of amusement to punctuate more serious or tense narratives. The media often played on references to human lab rats and the pathetic state of subjects. These included *No Angels* (S3 E3), *It's Always Sunny in Philadelphia* (S9 E8), *American Dad* (S4 E8), *Archer* (S3 E5),



*Testees, The Normals, 2 Broke Girls* (S1 E20), *Two and a Half Men* (S5 E5), *Malcolm in the Middle* (S6 E20) and *The Big Bang Theory* (S1 E15). In the otherwise serious UK detective drama, *Inspector Lewis*, an episode (S5 E3) started with a doctor placing pills into plastic cups before playfully saying, 'Call the guinea pigs!' The human guinea pig trope serves as an easy laugh line that communicates to the audience that the story is about medical research and that harm to the participant is likely.

Another example of the use of research participants as comic relief is in the comedy series *2 Broke Girls*. In one episode the main character Max, a waitress, convinces her coworker Caroline to join her in participating in a drug trial for money. After Max first mentions that she will be doing the drug trial, Caroline is indignant:

*Caroline:* Max, [that's] not one of those places where they use you as a guinea pig to test for side effects of new drugs that go on the market?

*Max:* Or as I like to call it, getting paid 500 dollars to roll the side effect dice and hope it lands on hallucinations. [audience laughter]

Predictably, Caroline is soon confronted with the need for quick cash. Max agrees to donate her share along with a portion of their savings if Caroline is willing to join the trial and earn a portion herself. The two women are portrayed throughout the episode as enterprising and resourceful, yet still desperate to earn money no matter what the risks are.

In addition to emphasising the characters' financial desperation, the programme also equates research participation with mental illness. In a later scene, Caroline peers at others in the drug trial and remarks, 'Wow, everybody looks so normal. This is more like sorority row than skid row'. But another participant, who identifies herself as a self-mutilator, interrupts and asks if she could room with them. Audience laughter ensues as the two main characters mock her and turn down her offer.

Even in dramas that deal more seriously with the risks of clinical trials, the suffering of research participants is written not to elicit sympathy from viewers but to enhance the comic value of the film or television show. An example comes from the soap opera-like hospital drama, *No Angels*. While the series takes a more serious tone overall, the participation of nurses and a doctor in a clinical trial is used for comic relief. In one scene, a male doctor says he just got 'the best night's sleep ever', which colleagues use as a pretext for asking if he's found a new sex partner. He admits that he's doing one of those 'things', a 'silly clinical trial'. A male colleague tells him that he doesn't know what they are giving him and that he might wake up with breasts. The doctor says, 'Exactly! It's a risk, but I'm interested in medical research'. After signing up for the study too, several nurses experience unpleasant side effects while the doctor who recruited them does not. Later, it transpires that the doctor, who is actually motivated by the money, has only been pretending to take the study drug, which explains why he feels fine and his co-workers have insomnia, ravenous appetites and rashes. The mounting misery of the nurses during the episode is the heart of the comic storyline, encouraging the audience to laugh at the side effects that participants experience.

One notable theme in the comic treatment of biomedical research focused on gender, sex and sexuality. We see this in the quote above in which a colleague warns another that he might

wake up with breasts. The humour in *Testees*, a Fox comedy series produced in Canada, builds heavily on anxieties linked to blurring the sex/gender binary as well as the pathetic desperation of participants. The two protagonists are depicted as financially desperate, but their desperation smacks of failed masculinity in a manner that differs from the financial desperation represented in *2 Broke Girls*. In the first episode, Ron and Peter, roommates and frequent participants at the research clinic Testico, discover that one of them is showing signs of pregnancy while the other develops a cartoonishly large penis. Filled with juvenile humour, the series later depicts the two unknowingly receiving sex reassignment surgery in one episode and in another, a chastity device that provides electric shocks in response to increased blood flow to the penis. Similarly, in a scene from the film *Bipolar*, the subject's brother warns him that the drug is 'going to make you impotent or lose your hair or grow a pair of tits'. Such references point to underlying concerns about sex/gender ambiguity linked to experimental biomedical research while simultaneously portraying subjects' desperation and misfortune as comic and entertaining.

A second theme evident in our analysis is the use of biomedical research participants as 'cautionary tales' (Montello, 2005) through which audience members might vicariously experience fears of the unknown while framing participants as the victims of fantastic side effects. Participants were simultaneously framed as financially desperate (in *The Normals*, *Testees*, *House*, *M.D.* [S5 E3], *Two and a Half Men* [S5 E5], *The Facility*, and *Law & Order SVU* [S10 E1]), mentally ill (*Special*, *Bipolar*, *Bug*, *2 Broke Girls* [S1 E20], *Control*, *Inspector Lewis* [S5 E3] and *Law and Order* [S15 E4]) or criminals (*Malcolm in the Middle* [S6 E20], *Control* and *Murdoch Mysteries* [S7 E5]). Extreme side effects in these instances were used to elicit shock and horror rather than humour, and government or pharmaceutical companies often played the villain in these tales. Representations of the government as villain were evident in *Dallas Buyers Club*, *Push*, *Fringe* (S1 E17), *Testees* (S1 E12), *Leverage* (S3 E5) and *PMS Cop*. Representations of the pharmaceutical industry as villains were evident in *Extraordinary Measures*, *All Saints* (S12 E6), *Special*, *The Facility*, *Drop Dead Diva* (S5 E1), *Law and Order* (S15 E4), *Leverage* (S3 E5), *Boston Legal* (S2 E11) and *Vile*.

As an example of a cautionary tale, the main villain in *The Amazing Spiderman* is a scientist who takes the experimental drug himself in order to regrow his missing arm. While the treatment at first appears therapeutically effective, he later morphs into a violent lizard creature that Spiderman, as protagonist and hero, must stop. Scientific experimentation appears volatile and unpredictable, even to scientists themselves. Meanwhile the re-growth of limbs, an ongoing fascination in science fiction (O'Neill, 2006), appears rather tame in comparison to the horror of a human–animal hybrid.

Extreme side effects are also paired with references to mental illness in the 2006 horror film *Bug*. Peter, played by Michael Shannon, is a military veteran who meets Agnes, played by Ashley Judd, in a run-down motel where they begin an affair. Bugs from a mattress soon pester Peter and infest the room. Agnes also sees the bugs and the two spiral into a panic as they coat the motel room in tin foil and hang bug zappers. Peter discloses his past participation in a military experiment that he now believes included the implantation of an aphid egg sack underneath the fillings in his teeth. In one particularly bloody scene, he



violently pulls out a tooth after listing off examples of military experimentation with LSD and the Tuskegee syphilis study. Agnes can only look on in horror. In the final scenes, a military doctor finds the pair and claims that Peter is actually suffering from paranoid schizophrenia. The suffering seems to be the product of mental illness, the bugs are only in their minds, but Peter lashes out and kills the doctor. The supposed victim now becomes the villain. Invoking schizophrenia appears to discredit the moral responsibility of the government for Peter's suffering while also removing him from the moral sphere of the audience. Both grotesque suffering and extreme psychosis are utilised to serve as cautionary tales about the potential misuse of military power. In the process, the main characters ultimately appear culpable for their own suffering as they douse themselves in gasoline and light the match together.

Across genres, participants in fictional media were framed as vulnerable or as members of stigmatised groups, such as the poor and mentally ill. The otherwise distasteful practice of allowing human suffering in the name of scientific progress can be directly addressed in these media while still producing felt amusement because of the social distance between the typical viewer and the pitiable subject. In another example, the horror film *The Facility* initially sets up an ensemble of relatable characters as new recruits in a clinical trial that goes grotesquely wrong. Each subject appears to undergo a psychotic break as the trial drug sets in, and each, in the order of dosing, goes on a violent and bloody rampage, hacking the study physician to death in a gruesome scene. The extreme and gory outcomes along with the shift towards mental instability provide a bloody distraction from the menacing company men who orchestrated (and survive) the trial. Again, the victims have become the villains. Outside of a brief image of the study's organisers surviving the massacre, the main source of terror comes from the drug's effects on the participants and not the company itself.

Some semi-realistic portrayals of biomedical research, however, do address the moral ambiguities of privileging scientific progress over individual suffering without comic or shock value. For example, in *Grey's Anatomy* (S4 E13-17; S7 E13-22; S8 E1), *House* (S5 E3, 11, 14) and *Law and Order* (S15 E4), a small subset of characters referenced the need to maintain emotional distance in order to allow science to proceed. In *Grey's Anatomy* (S4 E13), a doctor tells another who is running a trial: 'Don't get too emotionally invested in the patient'. Later in the same episode, another doctor says:

If it [the trial] doesn't go well, I'm killing people for sport... In a clinical trial, I'm experimenting, groping around in the dark, hoping to do the right thing.

Yet, in a later episode of the series (S4, E16) featuring this same clinical trial, three participants die within the first minutes of the episode, making them appear as mere objects to the experiment. Similarly, in the film *Control*, a security guard tells the main investigator that he broke the cardinal rule: 'Never get attached to your lab rat'. And in the popular series *House M.D.* (S5 E11), one doctor tells the other: 'Science is not about relationships or people, it's about results'. In these semi-realistic portrayals, however, the scientist's or doctor's own struggle with these emotional tensions is privileged over the potential suffering of participants. Elite experts exercise their power, not through coercion or deception, but in retaining the right to answer the question: what is science? The audience is invited to

sympathise with the emotional struggle of these elites rather than the research subjects themselves.

### **Clinical trial participants' use of fictional media depictions**

While fictional media reflect collective anxieties invoked by biomedical research, individual clinical trial participants themselves also use such popular depictions to manage their own anxieties surrounding their involvement in research. Participants' comparisons between fantasy and reality only rarely referenced explicitly the titles of films or television shows, but they nonetheless conjured narratives that were very similar to the comic and/or horrific themes we found in our own content analysis. In particular, participants drew heavily upon depictions from horror films; however, participants tended to tell these stories within the interview for laughs, literally laughing at themselves for subscribing to these fantastical representations of research. In their interviews they developed narratives, often combining the comic and horror aspect of the trial, that addressed the anxiety and fear they felt about the indeterminate risks of their participation in medical research.

As we have noted, healthy volunteers are motivated to enrol in clinical trials for the financial compensation they receive. Although there are risks of participating, they cannot benefit medically from the trial. As a result, many participants described a foreboding, but oftentimes vague, sense that participation in clinical trials is a dangerous undertaking. For example, Leo, an African-American man who had participated in 16 studies, recalled his initial thoughts about participating in clinical trials when he heard about them,

So when the opportunity was presented to me, it was kind of farfetched because normally you would hear about them doing research studies on TV or in movies or something, not an actual [place] where you live or close to where you live. So it was kind of, you know, farfetched for me. I had to wrap my brain around it, so to speak, and digest it. Like, really?

While Leo had trouble articulating what images from fictional media made it difficult for him to accept the idea of doing studies, his initial shock was processing the fact that medical research on healthy volunteers is something that actually happens, rather than something that is just done on television or in films. Charlie, a white man having done about 60 clinical trials, explained in a similar vein his initial hesitation to enrol in studies:

It's like, you know how your idea about something can completely influence how you look at something? ... There was a movie years ago about something like that, where they were doing strange things to people. So my point is, you know, I was a little paranoid about it. And then at a certain point, I think I was broke... and I went through with it.

The decision to participate, however, did not mitigate Charlie's worry and fictional media continued to affect his perceptions. He used humour as he recounted his feelings,

Like I said, I freaked out and was like-. [laughs] Well, you know, you look at-, I kind of saw these people in lab coats, you know, and it's-it's just perception, [but] it looked, it looked kind of like, well, 'What if they're doing, you know, who knows

what?’ That type of thing, you know, *Brave New World* stuff, like, who knows, you know. I’ve seen lots of movies. [laughs]

Participants’ references to media representation were often generalised and seemed to be associated with an indistinct sense of dread or concern about medical research. Even when we pressed participants for specific examples of media they had in mind, most were unable to describe a single film or television show featuring medical research that they remembered seeing. In the case of Leo and Charlie, both were pointing to the sense of paranoia that film and television cultivated in them, rather than specific plot lines they hoped to avoid in their own participation.

At times, participants’ anxieties focused on the research facility itself. Before they arrived, they were apt to project onto these spaces images of clandestine or illegal laboratories operating in illegitimate ways. Esteban, a Latino participant who had enrolled in 10 studies, described his initial thoughts about what the clinic would be like:

A friend mentioned it [research participation] to me... I never wanted to come... since I imagined a place that was ugly, dark, and-and weird where they did experiments on you. (translated from Spanish)

Other participants described their initial image of the clinic in similar terms; some even naming their fear that their organs would be removed (Raul) in a ‘medical dungeon’ (Virgil) run by ‘mad scientists’ (Renee) or ‘Nazi doctors with needles’ (Oscar).

Some participants imagined that humans and animals would be experimented on together as part of the research process. For example, Tracy, an African-American woman who had participated in eight studies, remembered her initial image of the facility:

All I thought in my head [about the facility was] it was monkeys and cages. [laughs] Someone told me that there’s a research lab where they have the animals in a wing next to the humans... so that freaked me out a bit.

Taking even further this idea of human and non-human animals together, Rachel, an African-American woman with experience in two clinical trials, pointed to Hollywood’s effect on her imagination:

*Rachel:* I think it was some movie I seen about a-a ape, and they was doing a study on him. And that’s what I always known a ‘lab rat’ to be, you know, the animals that they do studies on, the monkeys and stuff like that. So that’s what I always thought when I heard people in studies that they was just going to be like taking all this medicine and mixing them up with monkeys. [laughs]

*Interviewer:* Mixing them up with monkeys?! [laughs]

*Rachel:* And animals and, you know, just trying to see what the difference [was], and like-. [laughs] Yeah, real ignorant. [laughs]

*Interviewer:* So are the monkeys in one of the other rooms here? [laughs]

*Rachel:* Oh, I hope not! [laughs] I don’t want their blood, and they can’t have mine. [laughs]

Rachel made fun of herself as she related her initial misunderstanding about what the research experience might be like, and the interviewer [Jill Fisher] further turns the tone of a Dr Moreau-type thriller into a comedy, as both laugh at not only the impossibility of human and non-human animal blood being exchanged as part of the research study but even at the idea that monkeys could be housed in the research clinic.

Another important aspect of the horror-themed vision participants had of medical research was that they would be restrained in dehumanising and frightening ways. Oscar, a Hispanic man with experience in seven trials, recalled:

I mean, prior to even being in studies, I just assumed, you know, it's probably just you-you strapped to a table with cables running out of your body, out of whatever orifice, you know.

Similarly, Isaac, an African-American man who participated in 15 trials, recalled:

I was a little skeptical [about participating], like what are they paying you this for? What are they gonna do to you exactly? Are they gonna strap you to a chair? I can't leave? What-what are we doing here? What is gonna be going on?

Although clinical trial participation is voluntary and includes informed consent, these participants could not help but see research through the lens of a fictional experiment in which they would be coercively held in the clinic without knowledge of what they would be subjected to. Renee, an African-American woman who participated in clinical trials as her full-time job, explicitly referenced television for this image of research:

I didn't know anything about it, so I only knew what I saw on TV, and you know they don't depict it too well on TV. You know, you think of somebody that's got all these things plugged up to 'em, and they're just taking stuff, and they turn green and all that stuff.

As Renee hinted, the experimental drugs themselves also conjured images of being out of control and harmed by the research, a theme that participants, again, played for both horror and comedy. Grant, a white man who travelled around the country to participate in studies, referenced fictional media when remembering his initial anxiety about clinical trials:

I just, I didn't know what they were going to do, pump me up with drugs like in a movie or something? I didn't, I really didn't know. I had no idea what it was.

Evoking media themes about experiments as particularly threatening to masculinity, Jamal, a young African-American man participating in his first study, recounted a story he had heard about another clinical trial:

It's funny because the-the side effects. He [another participant] told me, what he told me was [that] it was, they-they mess with hormones and stuff like that [in the trial]. And it's possible [that] dudes would come out with boobs or something like that. And then the other side effect, basically, was it-it makes your penis, you know, shrink in size.

These fears about the effects of the drug typically focus on extreme and irreversible changes to the body. For example, Marco, a Hispanic man in his first study, described his previous hesitancy to enrol:

I never do [sic] it because I-I-I didn't want to do a study and turn into the Elephant Man [chuckles], you know? So that's my prime thing, you know, I don't want to take a substance and like I grow a huge ear or something, you know, or, or die.

By referring to the 1980 film, *The Elephant Man*, and moderating the reference by laughing, Marco was using an extreme example of disfigurement rather than a more commonplace illness to characterise his concerns. Many other participants articulated their fears of growing new body parts, like extra eyes, limbs and tails as a result of their participation, and usually laughed as they described these 'possible' outcomes. These comedy-laced fears were obviously not drawing on the particulars of the clinical trials in which they were enrolled; instead, they borrowed from cultural ideas about how medical research makes monsters out of research participants.

Participants' media-inspired fears about medical research not only signified initial anxieties about research, but they also helped to manage ongoing concerns about their participation in clinical trials. Specifically, the comparisons that participants made between the fantasy and reality of the clinic often explicitly rendered the clinic a normal and even comfortable space. For example, Mike, who identified as Hispanic and Native Hawaiian and was in his second study, asserted,

Initially, you watch television and you see these hospitals [represented]; you know, at first, I think it's going to be like a psych ward [laughs] where they knock you down, where they inject your neck if you go crazy. That's it. That's-that's the perception I had of it, and I thought, 'Man, I wonder how they're going to treat you in there?' ... but it's nothing but a positive experience for me.

Thinking initially that clinical trials might cause him to go crazy, Mike attributed 'Hollywood' as the source of not only his own but also the public's misperceptions:

That's why people's perceptions are so negative of clinical studies 'cause they start thinking like horrible experiments gone wrong, with-with Hollywood.

Likewise, in comparison to media portrayals of medical research, the actual side effects participants experienced were characterised as banal. Ray, an African-American man in his first study, commented on the contrast between what he expected and the reality of clinical trials:

I guess people think I'm going to turn blue, come out of here turning red, or growing an extra leg or something. I don't know. I mean, when you hear it, you think the worst thing possible, which most people do – which I did that first too. But once I got in here, it's alright, not like I thought it would be. I've taken worse stuff for your body than what they give you here, man, trust me.

The comparison of fictional side effects to real ones was particularly striking when the actual risks can, from an outsider's perspective, still appear rather unnerving. Rob, a Native

Hawaiian man who participated full-time in drug trials, provided a telling example of this trend. When describing his initial perceptions of clinical trials, Rob said,

Like I never heard of this [clinical trials], and ‘They do what?!’ You know, you gonna grow an extra eye, you gonna grow, you-you know, you hear all these things, you know.

In comparison, he considered the risks of the study he was participating in during his interview as ‘very minimal’, adding, ‘mainly it’s fatigue, heart rhythms, muscle joint pains, but it’s nothing, nothing’. In other words, in comparison to the possibility of growing an extra eye, Rob saw joint pain and even cardiac issues as mild side effects that did not concern him. Thus, by using fantasy as a contrast, participants could portray the actual trial side effects as nothing to cause alarm or worry compared to popular representations of extreme and frightening side effects.

## Discussion

Our findings indicate that popular depictions of research subjects in 65 movies and television programmes reveal collective and individual anxieties surrounding the risk of participating in biomedical research. Similar themes emerged in the narratives of healthy volunteers when they described their initial perceptions of the risks of clinical trials. In both data sets, elements of comedy and horror structured the story lines of research subjects. In fictional media, these genres framed subjects as either non-serious in their suffering or deserving of pain due to their stigmatised status, effectively removing them from the moral sphere that renders them deserving of the audience’s compassion (Nussbaum, 2001). This practice evokes extreme emotions (shock, fear, disgust and pity) while effectively distancing the audience from engaging in compassion for suffering others (Höijer, 2004). Certainly, comedy and horror are a means to entertain. But similar to other uses of humour to manage grief (Cain, 2012), we interpret this as a mechanism for managing negative collective emotions (discomfort and unease) elicited by incongruent cultural values associated with medical research. Healthy volunteers often used humour in precisely this way. We situate these collective anxieties about biomedical research within the broader risk society, which distributes responsibility for coping with risks away from those who produce them and onto those who are subjected to them (Beck, 1992).

As in comedy more generally, such strategies of ‘othering’ can be used as a comedic trope that dehumanises subjects (Lindsay, 2013). Humour can be used to curtail a sense of injustice and related feelings of righteous anger (Schrock, Holden, & Reid, 2004). Comedy, as ‘popular culture *par excellence*’, is a clear mechanism for delimiting social groups (Kuipers, 2006, pp. 374–375). In our media sample, comedies played up participants’ financial desperation, mental instability as well as willingness to risk sex ambiguity, thereby placing the participant rather than the trial at centre stage as the source of humour. Clinical trial participants used humour to brush away misunderstandings about the research enterprise.

Horror films made more direct references to psychosis and schizophrenia among medical research participants and used side effects to elicit shock and terror. Rather than seeing such



use of humour and fear as a means of cathartic release of deep-seated psychological tensions, we see them as both the product and ongoing production of biomedical power exercised through fictional media. Even in media that question the legitimacy of the biomedical industry, the suffering participant is the object of fantastical and grotesque horror. Among the few semi-realistic portrayals of biomedical research, the emotional struggles of physicians were privileged over the suffering of participants. For the healthy volunteers, this theme manifests in the distrust they exhibit in the information about clinical trials and the facilities that conduct these studies; they needed to remain vigilant that they were not duped into agreeing to participate in an illegitimate activity.

Fantastic portrayals of side effects in film and on television allow the public and individuals who participate in clinical trials to dismiss the real side effects of scientific research as both reasonable and ethical in light of the extreme contrast between the two. Certainly, there may be individuals who are dissuaded from participating in clinical trials because of the ways in which scientific research is portrayed in popular culture. In fact, participants noted that friends or family members also mentioned extreme side effects or popular media in explaining why they *would not* participate in studies, such as the risk of growing ‘three ear lobes’ (Philip) or ‘some weird horn’ (Stanley). While these representations might discourage some from participating in a clinical trial, they also serve to evoke and manage worries about the actual risks of biomedical research. For trial participants, a headache or some nausea was a minor inconvenience when compared to the prospect of a third limb. Such extremes serve as a point of reference, rendering the actual risks of trials as mild by comparison.

Masculinity also plays an important role in depictions of medical research participants. Where motives centre on financial gain, men make up the majority of test subjects depicted in fictional media as well as the majority of subjects in Phase I clinical trials (Fisher & Cottingham, 2017; Fisher & Ronald, 2010). As targets of a coercive and sinister caricature of science or victims of their own insolvency, depictions of men epitomise conceptions of failed masculinity. Such conceptions also explain the persistent references in media and among actual clinical trial participants to concerns about sex ambiguity and the risk that testing might turn them into women (see *Testees* and *Bipolar*, Jamal). In contrast, none of the women portrayed in the sample of fictional media or interviewed in our sample of healthy volunteers mentioned concerns about growing a penis, facial hair or other secondary male sex characteristics. Yet men’s concern for growing breasts or shrinking penises was evoked in both data sets. The emotions elicited from these portrayals are a mix of pity and comic relief rather than compassion or outrage as men are more likely to be seen as responsible and culpable for the fate that befalls them (Höijer, 2004; Moeller, 1999).

## Conclusion

Our findings throw light on the interplay between emotions, media and voluntary risk-taking that is of enduring interest to risk scholars (Zinn, 2006; 2008). Most studies of media and risk have focused on news and celebrity media (Tulloch & Zinn, 2011) with little integration of emotion management theory (Hochschild, 1979) into a discussion of fictional portrayals of risk. In this way, our analysis addresses Beck’s over-generalisation of media processes while also showing how, despite its seeming contradiction, clinical trial participants use

negative portrayals of biomedical research as a foil to manage their risk emotions and legitimise their decision to enrol in biomedical research. By conducting parallel analyses of the dominant themes represented in fictional media and the reflections of actual clinical trial participants on the risks of research, we further advance scholarship that typically deals with media and individual responses to it in isolation.

The development of medicine and technology involves testing on human subjects. While the risks of this experimentation could be used to critique science, popular depictions of medical research absolve these tensions within medical advancement by trivialising the humanity of participants and presenting extreme side effects that evoke humour and horror. A lab rat, it seems, can be anything except relatable. In tracing media representations from film and television to their use among healthy volunteers in Phase I clinical trials, we can see how fantastical portrayals of biomedical research are taken up by subjects actually engaged in such research. Our findings point to processes of emotion management at the collective and individual level. In this way, cultural repertoires of biomedical risk that originate in popular media can come to shape not only collective feelings about science but also the actual experiences of the individual subjects made vulnerable by its advance.

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