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'I'm still a hustler': entrepreneurial responses to precarity by participants in phase I clinical trials

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Abstract

This paper questions the implications of entrepreneurial responses to conditions of employment precarity by 'healthy volunteers' in phase I clinical trials in the United States. Such individuals are typically serial participants who often identify as professional volunteers and seek out drug studies as their primary source of income. Drawing on extensive qualitative research, this paper illustrates how healthy volunteers selectively import the identity of 'hustler' from the street environment and reposition it as connoting a set of valuable creative skills that give them a competitive edge over other participants. An entrepreneurial ethos allows them to view personal sacrifice and exposure to potentially dangerous drugs as smart investments leading to financially stable futures. These discursive moves normalize extractive, and at times dehumanizing, labour relations that offload expenses and risks to workers.

Keywords: Precarity; identity; creativity; entrepreneurialism; clinical trials; organizations.

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Introduction

This paper explores the creative adaptations and entrepreneurial schemes of individuals participating in phase I clinical trials in the United States. Individuals working in this sector as 'healthy volunteers' effectively sell access to their bodies for testing the safety and side effects of experimental drugs. These participants are contract labourers, many of whom travel great distances in the hope of screening for and being included in studies, which typically pay anywhere from $25 for a screening visit to $10,000 for a lengthy study (Fisher, 2015b). In some exceptional cases, individuals can earn around $17,000 for onerous studies lasting over three months (Madrigal, 2008).[1] If individuals are selected, they are usually *confined* to a clinic for the duration of the study (ordinarily lasting a few days to a few weeks), subjected to drug dosing and laboratory tests on a structured schedule, required to eat the dictated food and sleep when instructed and sometimes – out of intellectual property concerns on behalf of the sponsoring drug companies – relinquish their mobile phones and contacts with the outside world for the duration of their confinement (Motluck, 2009). The demands are clearly high on such workers, and they can also manifest extreme drug-induced side effects (e.g. cardiovascular irregularities, sleep paralysis with vivid nightmares, migraine headaches, incontinence, compromised immune systems, or death), in addition to being exposed to frequent and at times invasive or degrading tests (e.g. blood draws, lumbar punctures, stool collection) (Fisher, 2015a).

Healthy volunteers in the United States are primarily drawn from racial and ethnic minority groups, and most serial phase I participants are individuals who have a history of underemployment, with opportunities for income typically clustering in low-wage sectors (Fisher, 2015a; Fisher & Kalbaugh, 2011). Scholars have previously mobilized a trope of participants' economic desperation driving them to enrol in clinical trials (Sunder Rajan, 2007; VanderWalde & Kurzban, 2011), but this framing has the unfortunate tendency to erase healthy volunteers' active and engaged decision-making about study participation. As we will illustrate, healthy volunteers in phase I clinical trials are anything but passive in the face of employment precarity. They assert agency and creativity in locating potential studies, travelling hundreds or thousands of miles to clinics, gaming screening processes to increase their chances for inclusion, disregarding mandatory 'washout' periods between studies and maintaining 'healthy' bodies during periods when they are not in studies. Additionally, these workers cultivate entrepreneurial identities both within and beyond the clinics. Many of them see their participation in clinical trials as a means to an end, serving as an investment to support their planned start-up companies, real-estate ventures or artistic endeavours. Some of the participants exploit the captive audience in clinics to network with and sell goods to others, effectively importing informal economic activities into the space of formal ones. An entrepreneurial culture flourishes in these confined, temporary communities and can be witnessed, for instance, when individuals criticize others for blowing

their earnings on consumer goods instead of investing them in what they see as empowering business ventures.

In discussing the experiences of participants in phase I clinical trials, our aim is to question the implications of entrepreneurial responses to conditions of employment precarity. In other words, while it may be the case that casualization models of work have migrated up from low-wage employment sectors to cultural industries (Kalleberg, 2009; Ross, 2008), what are the effects of creative or entrepreneurial rationalities shaping the identities and practices of individuals working to survive on the margins? In what ways do such rationalities perform for those who do not feel that they have much choice, at present, about the work they do?

Clinical trials as work

There has been increasing scholarly interest in clinical trials as work, primarily emerging from the fields of cultural anthropology and science and technology studies. This research parallels the rise of a massive clinical trials industry that is made up of diverse organizations that sell their services to pharmaceutical companies to aid in the testing of investigational drugs (Fisher, 2009). While the development of such an industry is in many respects a uniquely American phenomenon (Mirowski, 2011), many of these companies, especially so-called contract research organizations (CROs), specialize in the global export of US models of clinical trials (Petryna, 2009). As a result, there has been an important expansion in pharmaceutical clinical trials being conducted both in the United States and Western Europe as well as in developing countries that have historically been resource-poor when it comes both to medical research and clinical care (Petryna *et al.*, 2006). In spite of the increased diversity in clinical trial sites, the United States remains the primary site of pharmaceutical research worldwide for all stages of clinical trials from phase I through post-marketing studies (Lytle, 2012).

In addition to focusing on the researchers and organizations that conduct industry clinical trials, trial participants themselves are now central to empirical inquiry and conceptual analyses. Examining who participates in industry clinical trials allows for engagement not only with their experience of participating in clinical trials but also with how the decision to enrol in research is shaped by broader patterns of social and economic inequalities (Fisher, 2013; Heimer, 2012; Joseph & Dohan, 2012; Kingori, 2013). For example, patients in the United States with inadequate access to health care might enrol in a clinical trial in order to have the opportunity to interact with health care providers and try an investigational drug that might ameliorate their medical condition (Fisher, 2007, 2009). The situation is even more dire in contexts with high mortality rates, pushing frontline workers to adhere to their own sense of ethics to help patients even when their actions are in conflict with the research protocols (Kingori, 2013).

With phase I clinical trials, it is primarily the economic context that dictates healthy individuals' interest in enrolling in studies because they are typically motivated by the financial compensation they receive in exchange for their participation. This context can vary dramatically. For instance, Sunder Rajan (2007) found that one CRO in India opened its clinic location in the mill districts of Mumbai where unemployment had skyrocketed due to textile mill closures, taking advantage of the perfect conditions for finding research 'volunteers'. In contrast, Tolich (2010) found that most healthy volunteers in New Zealand were students who instead of seeking income for their very survival were participating in phase I studies as a way to afford 'extras – a motorbike, a camera, a surfboard, a holiday to Nepal' (Tolich, 2010, p. 767). The US context exhibits similarities to both of these ends of the economic spectrum with many healthy volunteers enrolling in studies as their primary source of income while others use it as supplemental income. What might be unique to US phase I trials, however, is the 'professionalization' of healthy volunteers who identify clinical trials as their work. Abadie (2010) describes a group of anarchist 'professional guinea pigs' who have made a career out of participating in clinical trials, in part for the flexibility that this form of work provides. Labour is so central to their view of clinical trials that many of Abadie's informants are union activists, advocating for so-called guinea pigs to organize as a means to demand better wages and work conditions.

Drawing in part upon the work of Abadie (2010) and Fisher (2015a) for empirical examples of clinical trial participants, Cooper and Waldby (2014) develop the concept of 'clinical labour' by situating tissue donors, surrogates and research participants in a deeply historical analysis of work and labour relations. Specifically, by theorizing clinical trial participation in this way, they make visible the material transactions that are critical to the production of knowledge, especially when science is a hugely profitable enterprise forming what can be thought of as the 'bioeconomy'. Patients and healthy volunteers are both included as labourers in their assessment, with patients enrolled in a type of 'workfare' wherein the compensation for their trial participants is not in wages but in free diagnostic tests, drugs and medical oversight. Healthy volunteers are subjected to the same non-trial working conditions available to them, which can typically be characterized as casual, high-risk and precarious. In other words, whether in clinical trials or other employment sectors, work is never guaranteed and often tenuous.

With phase I participation, it is important to bear in mind that 'healthy' itself is an uncertain category because the ability to qualify for these clinical trials rests on meeting specific inclusion–exclusion criteria that are changeable depending on the needs of the pharmaceutical company. That is, the overall availability of clinical trials and the difficulty in assessing one's exact biological state on any given day means that healthy volunteers cannot count on enrolling in a clinical trial whenever they choose to do so. We perceive these work conditions for healthy volunteers as similar to other precarious labour in that it encourages creative or entrepreneurial responses to those conditions while responsibilizing

individuals for contending with their employment insecurity (Neff, 2012; de Peuter, 2011; Terranova, 2004). Just as an entrepreneurial ethos penetrates other sectors (Gill, 2007; Mumby, 2015; Roper & Cheney, 2005), it is taken up by healthy volunteers as an assertion of agency, allowing them to generate discourses of value and meaning for their participation in phase I trials. This may also, of course, further normalize exploitative conditions, but the phenomenon calls for empirical scrutiny to assess how individuals make sense of their own precarious relationship to the labour market.

Methods

This paper draws upon 178 semi-structured interviews conducted as part of a longitudinal mixed methods study of healthy volunteers' participation in phase I clinical trials (see Edelblute & Fisher, 2015).[2] From May to December 2013, we enrolled healthy volunteers in this larger study while they were participating in clinical trials at seven phase I clinics across the United States. Participants were enrolled so that our sample would be drawn evenly from clinics in the east, midwest and west of the country. This recruitment strategy enabled us to enrol a demographically diverse and representative sample of individuals who participate as healthy volunteers in clinical trials (Table 1). As is typical of phase I trial participants (Fisher & Kalbaugh, 2011), our sample is predominantly men (74 per cent) and racial and ethnic minorities (68 per cent), with 40 per cent self-identifying as black, 32 per cent as non-Hispanic white, 21 per cent Hispanic, 7 per cent as more than one race, 5 per cent as Asian, Native Hawaiian or Pacific Islander and 1 per cent as Native American.[3] Additionally, nearly 20 per cent of our sample included participants who were born outside of the United States. More than 60 per cent of participants in our sample were between the ages of 30 and 49, and 22 per cent were between the ages of 18 and 29.[4] Participants had a wide range of experience as healthy volunteers; approximately 20 per cent were participating in their first clinical trial, 30 per cent were enrolled in their second through fourth study, 25 per cent were enrolled in their fifth through tenth study and 25 per cent reported participating in more than 12 studies and upward to 200 clinical trials.

We also collected demographic information about participants' educational attainment, employment status and household income (Table 1). For many participants in our sample (50 per cent), the highest degree they received was a high school diploma or equivalent (GED), with approximately 29 per cent reporting they had taken some college classes. A smaller subset of participants (7 per cent) never finished high school or received a GED, and 11 per cent received trade or vocational training, such as certification in heating and ventilation, home inspection and cosmetology. Of those participants (33 per cent) who had received college degrees, 12 per cent had associate's degrees, 18 per cent had bachelor's degrees and 3 per cent had graduate degrees (which include master's degrees in music and psychology). As might be expected, it was only a small segment of our

Table 1 Demographics of study participants ($N = 178$)

	N	%
Female	47	26.4
Male	131	73.6
Age		
18–21	6	3.4
22–29	34	19.1
30–39	58	32.6
40–49	54	30.3
50+	26	14.6
Race/Ethnicity		
Non-Hispanic white	57	32.0
Black	72	40.4
American Indian	2	1.1
Asian	6	3.4
Native Hawaiian or other Pacific Islander	2	1.1
More than one race	13	7.3
Hispanic	38	21.3
Foreign born	35	19.7
Educational Attainment		
Less than high school	12	6.7
High school or GED	37	20.8
Some college	52	29.2
Trade/Technical/Vocational training	19	10.7
Associate's degree	21	11.8
Bachelor's degree	32	18.0
Graduate degree	5	2.8
Employment Status		
Full-time	30	16.9
Part-time	40	22.5
Self-employed	48	27.0
Not employed	58	32.6
Retired	2	1.1
Household Income		
Less than $10,000	30	16.9
$10,000 to $24,999	52	29.2
$25,000 to $49,999	70	39.3
$50,000 to $74,999	14	7.9
$75,000 to $99,999	7	3.9
$100,000 or more	4	2.2
Clinical Trial Experience		
1 study	38	21.3
2–4 studies	49	27.5
5–10 studies	45	25.3
11–200 studies	46	25.8

participants who were employed full-time (17 per cent). Approximately, one quarter of our participants had part-time work, but somewhat more (27 per cent) reported being self-employed.[5] Finally, nearly a third of our participants were not employed. Reports of household income varied based on the number of adults with whom participants resided as well as their calculation of the wages of non-intimate partners (such as parents or room-mates), but our sample was distributed with 17 per cent at less than $10,000, 29 per cent between $10,000 and $25,000, 40 per cent between $25,000 and $50,000 and 14 per cent at greater than $50,000 per year.

Precarity and identities as professional 'healthy volunteers'

We start from the position that the 'healthy volunteers' who participate in phase I clinical trials are independent contractors who are indispensable to the organizations for which they work and the industry as a whole. Drug development as we know it could not happen without these individuals allowing their bodies to be used to test drug toxicity and side effects, generating data that are transformed into intellectual property for pharmaceutical companies and are used to make decisions about which products to pursue (Corrigan, 2002; Fisher, 2015a). In this sense, these workers are engaged in a deeply embodied form of 'immaterial labour' (Gill & Pratt, 2008; Lazzarato, 1996) or 'clinical labour' (Cooper & Waldby, 2014), providing a service that results in valuable symbolic content. Notwithstanding the industry term 'volunteer', phase I participants are typically serial participants, many of whom adopt professional identities as participants and seek out drug studies as their primary source of income. In the sections that follow, we draw upon our qualitative data to review some of the motivations of these workers, how they perceive themselves in relation to precarious labour markets and the creative strategies they employ to maintain a competitive edge within the 'study game'. As we will illustrate, when healthy volunteers mobilize entrepreneurial narratives, they are doing important identity work, asserting hopeful visions of *future* autonomy and success in the face of the current unforgiving structural forces buffeting them. For most, entrepreneurial visions are subordinated in practice, as they accept the role of professional participant and seek degrees of relative economic security.

A means to an end

The threat of dead-end minimum wage jobs, unemployment or homelessness motivates many of our interviewees to pursue participation in clinical trials. Most of them acknowledge the potential risks of exposure to experimental drugs but either come up with rationalizations for their relative personal safety (e.g. being healthy, young) or criteria for not participating in studies they view as posing the greatest risk, either because of the condition being

targeted (e.g. mental illness, HIV) or the procedures involved (e.g. lumbar punctures, radiolabels). Still, economic insecurity compels these workers to seek out drug studies in spite of initial or ongoing fears about their safety. One interviewee explained:

> You could die, and seeing those words in black and white [on the informed consent form] that you can die, that really, it really took me back, like I read it a few different times. It's like, wow … So I mean I did have reservations, but I think there is I guess a *level of desperation* at first when, when somebody chooses that this is the way that, you know, that they need to make that next bit of money and that it's worth it, and they don't know what is going to happen to them health-wise. (F2411, biracial man, emphasis added)[6]

While many of our informants do communicate masculinist expressions of bravery, others connect this directly to economic insecurity: 'I wouldn't call them [serial participants] risk-takers, I'd just call them people with nothing to lose' (F2402, black man).

Sometimes any sort of job is difficult to come by, particularly for individuals who are considered by employers to be risky investments. Thus, a number of our interviewees claimed that they did not have any viable alternatives because of being older, lacking college degrees, being overqualified or having a criminal record. The anxiety from being in such a situation can generate feelings of gratitude for phase I work: 'These studies have been like a godsend [for me] because I mean, in today's world, you know, you're 50 years of age and if you need money and what do you do?' (C2401, white man). For individuals who are disqualified from many jobs because they were previously convicted of felony crimes, the options may appear to be black-and-white choices between exploitative or dangerous labour or illegal activities, which would most likely lead to further incarceration:

> [My friend] can't really work, or he can, but he figured he would make more money doing these [studies] than he would working [at a fast food restaurant] on the account that he's a felon, which they have a lot of people that do these studies are felons … I believe that most people would rather make money than go back to jail. (F2402, black man)

Some of our informants admit that they are hanging on 'by the skin of their teeth', staying in motels and living from day to day, just a step away from homelessness. Phase I studies can be a life-line for such people, especially if they have been denied employment everywhere else:

> Ever since December, as soon as this year started, I've been unemployed. I've been getting interviews here and there. I've been non-stop filling out applications, whether it's McDonald's, Foot Locker, anything. And nobody hires me. I don't know if it's because I have tattoos on my neck and my hands. I

> guess I'm overqualified when I put certain jobs, how much I got paid. You know, so it's been rough. So I find myself here at this study just because it's Mayday [a distress signal] for me. And that's why I'm here. I haven't been working all year, so that's-that's why I'm here. (F1110, Hispanic man)

With some exceptions, instead of internalizing blame, our interviewees see that being in an economic recession compounds their insecurity and limits the options available to them. They also treat phase I participation as a means to an end, striving to convert this access to financial resources into something bigger and better:

> My goal is to take the money that I do gain and invest it or save it to make an accomplishment. It's not like I'm trying to make a career out of it, but it has helped financially. So like my goal particularly is that I'm saving money, putting money to the side – besides paying bills – to buy small investments that leads to bigger things. So it's just a game plan. You gotta come in with a plan. (F2202, black man)

The reasons given for needing an exit strategy include recognition of the unreliability of clinical trial participation, concern about long-term negative health effects and lost time in terms of what individuals feel comfortable claiming as job experience. Even though participants operate as independent contractors and pay taxes, such employment cannot approximate levels of security associated with Fordist organizational relationships: 'If I'm, you know, doing studies, you know, I don't have a company contributing to a 401(k), you know, on my behalf, things like that. Like I'm not, I'm not climbing the corporate ladder' (F2411, biracial man). Furthermore, because of the stigma attached to participation in drug studies, many individuals do not tell their families or friends about their work, and they certainly would not put it on their resumés. Participating in clinical trials is viewed as liminal work, perfectly legal but also not quite a part of the formal economy, which makes it seem all the more important to leverage study participation for something else.

Entrepreneurial dreams and hustling

With plenty of time on their hands when confined for studies, the entrepreneurial aspirations of healthy volunteers multiply and spread. Our informants describe many different planned business ventures, ranging from promoting artists, to owning dollar stores or gas stations, to running clubs or bars, to purchasing and flipping foreclosed homes. These visions share underlying goals of being self-employed, especially being an owner or CEO not responsible to any other person, and, of course, being wealthy. As one participant who did not complete high school expounded:

> I'm the CEO of the company, but just really trying to branch out and really make it big … I'm not using this money [from clinical trials] to set me up to buy some

> grams and a pound of this and that [illicit] drug and hustle it. I'm not using this money to, you know, go splurging on a girl and be broke and then be alone … I'll be using that money to invest in my businesses. So I want to start my own management company, my own record label, independent record label. And then I want to use that money if I make it big or whatever, I eventually want to have my own security company, my own, I eventually want to have my own bar, my own club. That's my dream. So I can be a club owner. That's my personality. (F1110, Hispanic man)

This hustler identity is key to how many informants view themselves, as another boasts: 'I'm a hustler. So you could put me in the middle of the Sahara Desert, if there's three villages there, I'm going to make me some money' (F1329, black man). A different interviewee echoed the theme of leveraging his street experience of hustling and selling drugs to succeed both in clinical trials and in business ventures: 'I'm still a hustler, you know … I just took my same hustler mentality, and now I'm putting it towards something legal, you know? Which this [clinical trials participation] is a hustle too, you know?' (F1123, white man). In this formulation, hustling is both a fungible skill and scarce resource that can be used to gain competitive advantage over others in formal or informal economies.

Healthy volunteers with entrepreneurial aspirations see the time they spend in studies as productive. It affords them quiet space in which to hone their business strategies and network with others. For instance, one man explained:

> When I do these studies, it just gives me a lot of time to really, to plan, you know, 'cause I'm here all the time. It's like I might as well think about what I'm gonna do, how I'm gonna make money for myself … Like you see all of these papers, you know, all I really, all I do is write things down … I gotta list a lot of stuff here, and most of it is like, it has to do with some health, it has to with some houses, it has to do with some loans, it has to do, it has to do with a lot of stuff and what I wanna accomplish when I get out of here and a lot of people I gotta call. (F1423, black man)

Because there is a captive audience of potential customers or business partners, these self-described hustlers take advantage of that as well:

> I'll be profiting a lot more money next year with my business, so that's what I'm looking forward to. Right now I'm in the process of building clientele, and like, like I said, when I be doing studies, and also anywhere I go and meet people, I give them my business card. I give them my business cards to everybody I meet, you need your house cleaned? You need a home makeover or whatever, events planned or whatever like that. (F3460, black man)

In our visits to clinics to recruit participants for our study, we also witnessed this combination of hustling, networking and entrepreneurialism manifest in individuals selling gift baskets, roses, bootlegged DVDs and other merchandise to

each other. While not everyone harbours entrepreneurial dreams, this was clearly a dominant identity construct among our informants.

Because of the financial resources made possible through phase I clinical trials, many participants view eventual success with their entrepreneurial plans as guaranteed and – in neoliberal Darwinian fashion – blame those who do not succeed for their own failure, whether because of being stupid or lacking commitment. One man who has plans to make a fortune by buying houses, renovating them and renting them out, said:

> If a person is not wealthy from doing studies within like a 10-year frame, then they [are] just a fuck up, blow off money, show off, buy stuff they probably don't need. You know, 10-year frame, if you're not wealthy, then you're a fool, a real fool … Like, I got big ideas. I plan on making inventions and getting patents, and stuff like that. And I got money to do the stuff like that now. You get what I'm saying? (F2302, black man)

There is a perception that if people fail, that it is somehow because they lacked the requisite discipline to succeed. Another participant who is also involved in real estate articulated this position in a gentler fashion:

> I've seen people that, that have blown through money and it's like, wow, I mean you have a great opportunity to get ahead and really do something. And I don't like to be judgmental so I don't say anything, but just in my, thinking to myself, like man, you know, so I don't want to be one of those people. I want to make something out of it. (F2404, black man)

Based on our other interviews, it does seem accurate that there is a tendency among participants to use their earnings to pay off bills or purchase big-ticket items like plasma televisions, not necessarily to invest in outside business ventures. Part of this is definitely structural because when participants are released from confinement and finally paid, the large lump sum enables momentary extravagance that would not otherwise be possible and which can be used to acquire symbolic capital within their communities (e.g. friends or family members who cannot afford such consumer goods). What is perhaps more interesting, though, is the way that entrepreneurial narratives serve to rationalize exposure to risk in clinical trials, nourish dreams of a better life, and reposition street skills in hustling as unique assets instead of liabilities. All the while, the narratives ascribe personal failing as the reason for people's inability to become rich, or just make ends meets, in the current economy.

The job of study participation

Volunteers in phase I clinical trials might be drawn to the job initially out of a sense of desperation or limited viable alternatives, and entrepreneurial narratives help compensate for the uneasiness individuals feel in this occupation. However, as they come to accept the identity of professional participant,

these individuals approach participation in clinical trials as a competitive 'job' that requires a significant amount of uncompensated labour in order to secure the possibility of being chosen for studies.

The labour of trying to secure work begins with the drudgery of finding available studies, travelling great distances, often across state lines, to the clinics, successfully screening for studies and lining up and timing the next study after that one. In order to be successful with scheduling work, one must be diligent, patient and systematic:

> It's true that you-you can miss out on the really good studies if you're not calling every day … I'd probably get in more studies, better studies, if I would, did spend that-that much time calling every day, but it's tedious, all the calls and waiting on hold forever and going through a long, you know, description of the study and mostly it's being on hold forever … So if you can deal with that, you know, several hours a day, you know you're gonna get a lot better studies more often. (F2412, white man)

Participants also stress the need for developing relationships with clinic staff so that one is given insider information about future studies, especially well-paying ones. While some find this to be a tiresome process or unrealistic expectation given other life demands, others approach calling clinics as a challenge akin to seducing women:

> You know when you're confident, you're confident all the way. It's like going for a girl, female. If you're half-stepping,[7] she's gonna sense it, they're like animals, like if you half-stepping it, they're gonna sense it: 'Oh, this guy's scared of me, he's not getting my number, he's a little wimp, you know, I like a confident man', you know what I mean? So studies are like that, you have to go into 'em with that, that mindset, like I'm gonna get in, you know. (F2406, biracial man)

Such masculinist orientations fit well with the hustler identities of many participants, especially those who view their experience of drug side effects as a sign of bravery or strength. More than that, the narratives also discursively emasculate individuals who are unable to locate, screen and qualify for well-paying studies.

In order to maintain a tight schedule of studies, which is necessary for achieving a sustainable income, participants routinely violate the stipulation that they observe a minimum 30-day washout period between studies. The rationale behind this requirement is that experimental drugs, if present, can be purged from participants' bodies before individuals are exposed to additional drugs. This is intended to maintain the integrity of the science and also protect participants from dangerous, unintended drug interactions. In practice, though, it is rare for professional participants to observe such washout periods voluntarily:

> So it's supposed to be 30-day washout period, but nobody does a 30-day washout period … You can always, you know, take supplements that will, you know, boost your hemoglobin and your iron back up to where it's supposed to be. So otherwise, I mean a lot of people, if you do this for a living, waiting every 30 days, you're not gonna make any money. So a lot of us, you know, jump from one study to another study within like a week or two weeks. (F2410, white immigrant woman)

Some of our informants even confess to being enrolled in multiple studies *simultaneously*, which is technically possible if they are in an 'outpatient' component of studies that require follow-up testing at scheduled intervals rather than sustained confinement. Because clinics maintain their own records of when individuals participated in studies last, healthy volunteers simply rotate among clinics and make certain that they allow 30 days to pass before returning to the same site. As a rule, volunteers also try to avoid studies that require follow-up visits after the confinement period because such visits can extend their 30-day wait period and can also introduce additional expenses, such as commuting to a distant location or feeling compelled to remain in a region, perhaps incurring motel and food expenses, as they wait for the scheduled follow-up tests.

Many other job-related expenses and risks are offloaded onto participants, making the mitigation of such things also part of the ongoing labour of this occupation. For instance, several participants told us about incurring unreimbursed medical expenses after manifesting frightening adverse effects while being dosed with experimental drugs in phase I clinics. One woman described such a situation where her blood pressure spiked to dangerous levels:

> Yeah, even the nurses got scared. You know, they were like, 'Oh my God', 'cause like I said, they even brought a crash cart, because I mean it was just I had a blood pressure of 172 and a heart rate of 144. Come on … So and from that, I got banned from a couple of places due to [the fact that] my ECG's were abnormal [afterward] … Well, they told me to go see a cardiologist. They told me, and they told me I cannot participate in any studies in [that clinic] until I show 'em that I went to a cardiologist.
>
> *Interviewer: Okay. Is that expensive?*
>
> Yeah, it was about $3,000.
>
> *Interviewer: Wow.*
>
> Yeah, my insurance only covers some of it. So then I brought the, the bill to them [the phase I clinic] and they refused paying it. (F2410, white immigrant woman)

Experiences like this, and other participants' awareness of such situations, generate wariness of risky studies. One man described being 'burned' a few times by the long-term effects of studies:

> I've been burned a couple of times. Like I did one, I did one [study] at [a clinic] where it raised your cholesterol … which I didn't mind doing, but then I found out it–it kept your cholesterol up for a long time, so I, I wasn't able to get into other studies for like several months afterwards, and I had to really work to get my cholesterol down. Then there was one that messed-messed with your white blood cell count. So there was a couple of years that my white blood cell count was really low, and I was getting declined from, rejected from studies because of that, and I could trace it back to the study that-that-that was a side effect. So my-my main concern is will the side effects prevent me from getting other studies, you know? (F2412, white man)

What these stories reveal is that while participants may be concerned about health risks caused by study drugs, some of these concerns are, in fact, motivated by a fear of perceived risk to future employability.

Voluntarily taking on additional expenses and making personal sacrifices can be viewed as necessary 'investments' in order to succeed in this occupation. For example, because of restrictions on women 'of childbearing potential' participating in phase I studies, out of fear of (legal liability for) potential birth defects, pharmaceutical company sponsors sometimes require proof of surgical sterilization before women can screen for studies. One woman describes her decision to become sterilized for this work:

> This is kinda embarrassing to admit. Nobody knows this, not one person in my life, not my family or friends, but I got my, I got a procedure called Essure, E-s-s-u-r-e. There were so many good paying studies coming up for women who were surgically sterile or postmenopausal and I was never qualifying for them. Even though I was completely abstinent, they [the clinics] don't believe you, you know. So I had health insurance and they paid for this procedure. It was just an inpatient visit basically. It was a little more painful than they thought, [than] they said it was going to be, but anyway. So then I became a surgically sterile category and I could get into these, quite a few of these better paying studies. Like the $6,000 one was for women who are surgically sterile. So even though I had, I had no chance of getting pregnant, I did that [voice drops to a whisper] just to qualify myself for better studies. (F2421, white woman)

In a less extreme vein, other participants describe compromising their moral principles, such as opposition to genetic sampling, out of fear of being excluded from studies if they object:

> They say it [giving a genetic sample as part of the study] doesn't affect whether you'll be accepted into the study, but I don't trust that. I bet it does affect it, so I, so due to that pressure, I go ahead and accept the genetic testing anyway, even though I'd rather not. (F2412, white man)

A sense of precarity, therefore, motivates not only participation in what is perceived to be a risky and stigmatized line of work; it also compels financial and personal sacrifice for the possibility of being competitive at it.[8]

Tricks of the trade

Participants in phase I trials engage in a dizzying array of creative practices to make a living out of studies. Maintaining healthy bodies, through lifestyle choices and innovative experimentation with diet and supplements, is one way that participants prepare themselves for employability. Thus, with much variation, they work in between studies to maintain their competitive edge by dieting, exercising, not smoking, not drinking alcohol or caffeine, avoiding recreational and over-the-counter drugs, getting sufficient sleep, drinking lots of water and so on. As one participant explained, the extreme scrutiny and legibility of one's body obliges such an approach: 'They [clinic staff] will look for your blood pressure, your whatever things, BMI [body mass index], your heart rate, your everything, your urine, your blood samples, everything. So you have to be healthy [at] any time' (C2405, Asian immigrant man).

Consequently, participants develop sophisticated regimens for staying healthy and keeping their lab results within acceptable ranges. They work out regularly between studies, but taper off right before screening so that their liver enzymes will not be elevated, which would lead to them failing the screening. They eat blueberries, arugula, spinach, kale, salmon, yogurt, raw garlic, and other expensive health foods to maintain measurable health. They develop nutritional and medical expertise, observing their lab results and adjusting behaviour accordingly. Some take milk thistle, ginseng and flaxseed to clean out their systems and get their liver enzymes back to acceptable ranges; most take multivitamins and iron supplements, sometimes even sneaking them into facilities, in order to boost the depleted hemoglobin and iron in their blood.

They are also not opposed to experimenting. One participant, for instance, recommended detoxification through the consumption of charcoal:

> Charcoal has the ability to remove toxins from your body, has the ability to remove 800 times the weight of whatever amount of charcoal you induce … You can get your fireplace all ready and go in and then maybe burn some good oak and-and out of that, what's left, you know the-the-the carbon itself? Take it out and grind it, you know a good clean piece of oak? Or if you can't get it like that, then you can go to the health food store and buy charcoal. It's called activated-activated charcoal. It comes in capsules, and then if you do about two or three teaspoons in a cup of water, stir it, you know, and then drink it like two or three times. That'll scrub you. It'll take out whatever, you know, and you do it two or three times say after a study, say you do it two, three days in a row, you're pretty much cleaning out a lot of what was left in there … It'll tone you back up and you're ready [for your next study]. (F3431, white man)

Similarly, another participant consumes gallons of water with lemon juice to detox:

> I have an 11-day washout period [before I start my next study]: a lot of lemon water … Lemon water dilutes and cleans our your body toxins and everything … That's the best way to clean out your system as far as like, as far as the [investigational] drug, as far as this drug, it's a lot of gallons of lemon water. (F2402, black man)

The point of such practices is to speed up the body's washout period (if not the clinics'), adjusting it to the schedule of healthy volunteers so that they can get back to work more quickly.

Because the screening process is the point at which most participants are either included or excluded from a study, this becomes the moment subject to the most manipulation by prospective volunteers. First, as we have already mentioned, many participants do not observe stipulated washout periods, so they mislead screening staff about when they last participated in studies. Second, participants will screen for multiple studies scheduled for the same dates, and if they are selected for more than one study, they will choose the one that best fits their criteria (e.g. best pay, fewest follow-up visits, safest, most convenient). In effect, they regularly hedge their bets. Third, if studies require that individuals live in the area, which is something that could give clinics confidence in participants returning for follow-up visits, some admit to listing addresses of acquaintances or foreclosed homes rather than their real places of residence. Fourth, if possible, they will alter their bodies to increase their competitiveness for the requirements of specific studies. For example, if they are told what the acceptable body mass index (BMI) range is for a study, they can either gain or lose weight in advance to meet that criterion. This can extend to other measurements beyond weight too, as one interviewee explained:

> It's funny how I did the cholesterol study because I don't have high cholesterol, just saying. But it didn't have to be high cholesterol, it had to be slightly elevated. So in order to get in that study, I know this is going to seem funny or weird, I ate a lot of eggs and fish over the course of two weeks to get my cholesterol slightly elevated just enough to get in. And I did. Yeah. (F2402, black man)

Fifth, participants can fool so-called objective measures, such as BMI, by doing things like adding padding in their socks to add an inch to their height, thereby lowering their measured BMI so that they can qualify for studies. Sixth, screening can be rigged in one's favour by having one's friends sign up for screening appointments, so that the quota of potential volunteers is filled, but then those friends intentionally neglect to show up. These are just a few of the many tricks that healthy volunteers use to game screening processes.

Getting into studies is not sufficient, though, because individuals must also strive to maximize their financial gain. Once enrolled in a study and confined

to a clinic, participants can also manoeuvre to be dismissed early if they know it will not cut into their funding. One interviewee explains the nuances of this from his experience with a study measuring blood pressure:

> That was a memorable study because they served us this salsa that had like 1,280 milligrams of sodium, so people knowing that [for this particular study] once their blood pressure goes up, they're going to be able to go home, you have people that are trying to eat, you know, all this sodium, and they're putting salt in water and drinking it so that their blood pressure will go up so they can get sent home with the full money. And then that-that's pretty funny, right? Then you got the one guy that doesn't have money to leave once the study's over, so he doesn't want to get sent home. So he doesn't eat the salsa. So he doesn't have any salt on his food because he doesn't want to get sent home early 'cause he can't afford it. He's not gonna have any money until the study, until the study gets out and he gets his direct deposit. (F2411, biracial man)

Clearly, gaming studies for one's personal benefit is highly contingent on one's current financial situation: where some view getting out early as freeing up time for more work, others see it as introducing additional hardship because they do not have the resources to stay at a motel or travel home. These examples are indicative of the agency and creative responses of participants as they attempt to succeed in this competitive labour market.

Conclusion

This paper has explored the identities and practices of individuals participating as healthy volunteers in phase I clinical trials, with specific attention to their mobilization of creative or entrepreneurial responses to precarious labour conditions. Rather than passive 'volunteers', we see instead workers who are actively trying to shape the opportunities they have for income in an unpredictable market. Such healthy volunteers are essential contract workers for the clinical trials industry and the many ancillary organizations that conduct pharmaceutical studies, yet many of these workers participate out of a sense of profound financial need. An entrepreneurial ethos allows them to view personal sacrifice and exposure to potentially dangerous drugs as smart investments, as stepping-stones to more financially stable and fulfilling lives. Creativity becomes both a means of competing with others on the margins, for inclusion in studies, and an expression of agency that affords a sense of personal satisfaction. Especially interesting are the ways that individuals construct their identities as professional participants. They see clinical trials as a job for which they must diligently train in order to strategize for the possibility of employability. They import the identity of 'hustler' from the street environment and reposition it as positive, as connoting a set of valuable skills that give them an edge over

others. For individuals who have little symbolic capital on which to draw, this move builds their sense of self-worth and offsets any shame associated with participating in stigmatized human experimentations.

Whereas insecure and casualized models of work have permeated across employment sectors (Gregg, 2011; Neilson & Rossiter, 2008; Ross, 2008), the adoption of creative or entrepreneurial identities by low-wage workers, like phase I participants, indicates a cultural shift that performs on several levels. Various acts of non-compliance and ingenious scheming may generate pleasure for these workers, but these acts are also necessary for them to subsist. In this sense, we can situate the creative manoeuvres of healthy volunteers in a deeper history of tactical responses by the poor to survive in hostile circumstances (Gilliom, 2001; Scott, 1985; Wacquant, 1998). At the same time, these creative responses do nothing to challenge the structural conditions of precarity, and they may unwittingly solidify these conditions by normalizing extractive, and at times dehumanizing, labour relations that offload expenses and risks to employees.

Because logics of self-exploitation undergird much contemporary creative work and entrepreneurialism, it is important to critique these constructs and their effects. Our findings build upon the valuable scholarship theorizing precarity in other sectors. Some have analysed those working in creative industries, including television programming, publishing, graphic design, advertising, music and software coding (Neff, 2012; de Peuter, 2011; Terranova, 2004; Umney & Kretsos, 2015). Others have noted how many organizations have learned from technology companies to cultivate 'fun' work-places that encourage total worker investment and team participation, which serve as soft mechanisms of social control to normalize exploitative and ultimately insecure work conditions (Fleming, 2007; Mumby, 2013; Ross, 2003). Still others have shown how new media technologies facilitate the colonization of personal spaces and identities by professional ones, while individuals shoulder the burden and cost of constant re-skilling to maintain the possibility of future employability (Gill, 2007; Gregg, 2011).

In the context of phase I trials, our interviewees mobilize creative responses to manage their experiences of a generalized economic precarity as well as the insecure labour of clinical trials. As in sectors with more cultural capital, an entrepreneurial ethos becomes an important mechanism for healthy volunteers to assert agency and generate discourses of value and meaning for the work they do. Against this backdrop, however, entrepreneurial dreams may act like a will-o'-the-wisp, luring participants into long-term exposure to potentially dangerous experimental drugs for the elusive promise of eventually becoming rich doing what they love.

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Notes

1 Although these amounts may sound significant, based on preliminary data from our longitudinal study, most participants have a difficult time finding sufficient work in studies to stay above official poverty levels.

2 The University of North Carolina at Chapel Hill Institutional Review Board reviewed and approved the research protocol. As part of enrolment, participants completed an in-depth semi-structured interview exploring their history of participation in phase I trials, their perceptions of the risks and benefits of these clinical trials, the factors influencing their decisions to participate in studies, their experiences with the study staff and other participants as well as their confinement to the study facilities and their routine health behaviours, including diet, exercise, as well as use of tobacco, alcohol, illicit drugs, over-the-counter medications, prescription drugs and contraception. The interview also included questions about participants' employment history, household configuration and economic stability. Interviews lasted an average of 70 minutes and ranged in length from 21 to 164 minutes, with much of the variability resulting from the number of clinical trials in which participants had previously enrolled.

Interviews were transcribed in full, all identifying information was removed to ensure confidentiality and then the files were uploaded to Dedoose qualitative software for coding and analysis. Coding was a multi-staged process that began with the development of a code structure based on open coding of several transcripts. New codes and sub-codes were added as new themes emerged from the data. Each transcript was coded by at least two members of the project team, and a detailed memo was written for each transcript to encapsulate the major themes of the interview, especially in regard to participants' perceptions of risk, clinical trial decision-making, their travel for clinical trials and a categorization of the volunteer 'type'. Through the process of writing memos and categorizing participants into types, the participant as 'entrepreneur' emerged from our data. We further developed the theme of entrepreneurialism by refining our codes and analysing the transcripts through this lens.

3 Data about ethnicity was collected separately from race, so the numbers do not total to 178. Hispanic participants also identified as white, black and more than one race.

4 Note that only six participants in our sample were between the ages of 18 and 21, indicating that very few healthy volunteers in phase I trials are traditional college students.

5 Many participants reported having multiple businesses through which they drew income, and clinical trials were one such activity that made some participants see

themselves as self-employed. We used participants' self-reports for employment status, so we did not standardize how clinical trial participation would count as work.

6 Participant IDs used throughout this paper give some information about each person. The letter indicates if the person was randomized to the full-participation ('F') or control ('C') arm of our study (for more information about this part of our study design, see Edelblute & Fisher, 2015). The first number of their ID indicates the region of the country from which they were recruited: '1' is East, '2' is Midwest and '3' is West. The second number indicates their clinical trial experience: '1' is first-time participants, '2' is second-time participants, '3' is third- through fifth-time participants and '4' is participants with six or more trials. The final two digits of the ID are simply consecutive numbers to create unique IDs for each participant. To operationalize our system, the gentleman quoted here with the ID of F2411 is in the full-participation arm, was recruited from the Midwest, and has participated in at least six studies.

7 'Half-step', in this usage, means 'to start something with no intention of finishing' (Urban Dictionary, 2014).

8 Our informants describe numerous personal sacrifices endured for this work and the confinement required by it: missing their children's birthdays and graduations, feeling unable to date or have long-term relationships, losing friends because of not having time to go out with them – and many more.

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