

Risk and Emotion Among Healthy Volunteers in Clinical Trials

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Abstract

Theorized as objective or constructed, risk is recognized as unequally distributed across social hierarchies. Yet the process by which social forces shape risk and risk emotions remains unknown. The pharmaceutical industry depends on healthy individuals to voluntarily test early-stage, investigational drugs in exchange for financial compensation. Emblematic of risk in late modernity, Phase I testing is a rich site for examining how class and race shape configurations of emotion and risk. Using interview data from 178 healthy trial participants, this article examines emotion and risk as mutually constituting processes linked to biographical context and social structure. Biographical events like economic insecurity and incarceration influence how risk is felt by providing comparative experiences of felt risk and felt benefits. Such events, in turn, are structured by class-based and racial inequalities, linking class and race positions to primary emotional experiences of risk.

Keywords

risk, emotion, race, class, gender, pharmaceutical industry

Risk is an inherent feature of contemporary society. Macro-level sociological work has theorized its relationship to social institutions (Beck 1992; Giddens 1990) and its fluid and constructed nature in relation to emotion (Lupton 2013; Zinn 2008). While unequally distributed across social hierarchies, the forces that shape the distribution of risk and risk emotions remain unknown. As one engine of risk distribution, the pharmaceutical industry generated an estimated \$447 billion in revenue in 2015 from drugs on the market (Daemmerich 2013), many of which have uncertain therapeutic benefits and devastating side effects (Light 2010). As part of the process of moving new drugs to market, the industry relies on the

participation of healthy individuals in Phase I clinical trials (Corrigan 2002). Healthy research participants are used to capture data about a drug's safety and tolerability, and because there is no potential for medical benefit, they are compensated financially for their

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participation. Without this pool of willing, and often eager, participants, drug development would not pass the crucial first phase of study before undergoing testing on sick patients to determine a drug's efficacy in treating an illness.

While necessary to the pharmaceutical companies and research clinics conducting such trials, healthy individuals have clear incentives to avoid the health risks of Phase I testing. The actual risks of such clinical trials depend on the product being tested and the procedures being used, but adverse events are relatively common in healthy volunteer trials. One study reported on 10 years of adverse events occurring in a single clinic and found that 65 percent of their 1,015 healthy volunteers experienced at least one side effect of an investigational drug (Sibille et al. 1998). The most common effects were headache, diarrhea, and indigestion. More serious problems occurred less frequently, with approximately 4 percent experiencing a severe adverse reaction (Sibille et al. 1998). Indeed, healthy volunteers have died or suffered long-term health consequences of their participation, but these examples are rare (Wood and Darbyshire 2006). One striking case occurred in January 2016, where healthy volunteers suffered death and injuries in a drug trial in France (Hawkes 2016). Previous social science research on healthy volunteers has shown these individuals to be repeat participants who become quite savvy about the differential risks of studies and trusting in the research oversight afforded by the typical in-patient structure of Phase I clinical trials (Abadie 2010). Additionally, serial participants' transient experience of adverse effects can also desensitize them to the risks (Fisher 2015a).

But how is it that healthy individuals come to willingly and even eagerly participate in such a risky activity? As a subpopulation, healthy volunteers can offer new

insights into how emotion and risk are shaped by unequal structural positions as volunteers confront unique biomedical uncertainties in Phase I trials. Drawing on 178 semi-structured interviews with a national sample of U.S. healthy volunteers, this article investigates the interplay between participants' perceptions of and feelings about the risks of clinical trials in light of the economic benefit. Financial need dominates participants' narratives about their enrollment in studies, but it is their feelings about their economic circumstances that are contrasted with their feelings about the risks and benefits of trial participation. Moreover, experiences of the criminal justice system serve as justification for some healthy volunteers' participation in such a way that mitigates feelings of fear and worry and intensifies feelings of gratitude and happiness about the opportunity to participate in clinical trials. We argue that risk and risk emotions be analyzed as mutual processes partially explained by the intersection of structural conditions with personal circumstances, such that participants leverage their emotions as the rationale (or rationalization) for their participation in Phase I trials. Rather than engaging in rational cost-benefit analyses, participants explicitly reference the emotions that emerge from comparative costs and benefits as fueling their decision-making process.

BACKGROUND

Risk

We situate our analysis of healthy volunteers within the sociology of risk, emotion, and the recent cross-section of these two fields. The sociology of risk has flourished in the last few decades with Beck's (1992) work on the "risk society," Giddens's (1991:122) take on the "dark side of modernity," and Lupton's (2013:634) theorizing of the "emotion-risk assemblage."

Beck's work in particular posits large-scale societal changes in how risk is fundamentally construed, looking at risk as a pervasive element of everyday life within the "second modernity." Stemming from technological and scientific advances in post-industrial societies, risk is unequally distributed among social groups so that established institutions, such as science and medicine, are insulated from the risks they produce to the citizenry. In this way, institutions retain their legitimacy despite their problematic features, including the byproducts that have the potential to compromise health and social wellbeing.

Scholarship within the sociology of risk distinguishes between voluntary and involuntary risk-taking, with Lyng's (1990) notion of "edgework" focusing on the experiences of voluntary risk takers who push the boundaries and limits of "sanity and insanity, consciousness and unconsciousness, and the most consequential one, the line separating life and death" (Lyng 2005:4). Yet even when examining occupations and activities that Lyng and others define as edgework, such as search and rescue volunteers (Lois 1999, 2005), firefighters (Desmond 2007), and military enlistees (Silva 2013), the distinction between voluntary and involuntary is blurred. At the root of such distinctions is the tension between agency and structure that undergirds sociological theory (Archer 1990; Hays 1994). At face value, the risks that healthy participants in Phase I trials take appear voluntary; within the industry, participants are even referred to as "volunteers." And yet conceptions of voluntariness rarely take into account the structural incentives that make some individuals more likely to "volunteer" to take a risk than others, especially when seeking financial compensation for their participation (Fisher 2007, 2013). Certain forms of risk fall disproportionately onto

different groups in society (Desmond 2007; Hayenhjelm 2006). As Desmond states, "because the distribution of professional risk takers reflects the established social order, to study risk is to study power and inequality" (2007:9). Prior research on risk, though, has focused primarily on the edgework of "white, middle-class, adult males" (Lyng 2005:11).

The sociology of risk has also examined the reciprocal relationship between risk policy and perceptions (Bröer 2007), as risk perceptions can serve as an impetus toward constructing a new disease category (de Graaff and Bröer 2012) as well as a catalyst for activism and the construction of new social problems (Bröer 2007). Extending this prior research, the present study examines *how* volunteers come to take on the risks of medical testing. How does social position shape the risk perceptions and emotions of healthy volunteers—a population disproportionately composed of poor and working-class racial minorities (Fisher and Kalbaugh 2011)? In doing so, we counter the "surge of individualization" (Beck 1992:87) within a risk society that diverts attention away from the social causes of risk while also examining risk among racial minorities and members of the lower and working classes.

Emotion and Risk

Bridging the literature on risk and emotion, Lupton's (2013) theoretical approach centers on the mutually constituting nature of each: "Emotions create risks and risks create emotions" (641). Risk, she argues, cannot be meaningfully separated into emotional and analytical components as psychological models have suggested (see Slovic et al. 2004). Nor can risk be theorized separately from emotion, as the socially situated construction of risk occurs simultaneously with feelings (and the management) of fear

and anxiety surrounding future-oriented projections of harm. This perspective counters the “techno-scientific enterprise” championed by risk analysis in fields such as mathematics, engineering, and psychology, which presuppose a rational-choice actor intent on making calculable and pragmatic decisions (Lupton 1999). For Lupton, risk processes are inherently emotional processes and they unfold in ways that might not always appear rational or consciously calculable. Following Lupton and others (Taylor-Gooby and Zinn 2006; Zinn 2006, 2008), an empirical investigation of the links between emotions and risk is needed to address lingering gaps in this field.

Emotions, like risk, are linked to social conditions that transcend individuals (Hays 1994). Along with constructions of the self, emotions emerge from situational frames (Goffman 1959; Hochschild 1979; James 1890) that shape the experience of pre-reflective emotions (as “primary acts”) and their management (as “secondary acts”; Hochschild 1979:552). Emotions, as both primary and secondary acts, can operate as both conscious and nonconscious modes that can become a source of self-knowledge. Emotion “is a body’s processing of social conditions, of its context” (Gould 2009:31) rather than an outcome of rational and conscious considerations of costs and benefits.

Emotion management—often a conscious, secondary act—aligns feelings and/or their expression with the emotions deemed culturally and situationally appropriate. Yet individuals do not freely choose from a limitless set of frames or ways of thinking and feeling, but rather frames are drawn from the dominant culture that posits its own logics and feeling norms (Hochschild 1979, 1983; Shott 1979). Culture constricts the repertoires available to individuals as they manage feelings, while cultural frames themselves are *constricted* by the relative

hegemony of different institutions within society, such as biomedicine.

While there has been a plethora of emotion research on gender (Cottingham, Erickson, and Diefendorff 2015; Erickson 2005; Erickson and Ritter 2001; Simon and Nath 2004), relatively less empirical work has attended to the links between emotion and race and class. Existing research on class has a strong focus on the emotional resources that children gain from parents and education (Cahill 1999; Froyum 2010; Gillies 2006; Reay 2004). Research on race has predominantly looked at the emotional experiences and management of African American men and women in professional occupations, including college professors, airline pilots, and flight attendants (Evans 2013; Harlow 2003; Wingfield 2010). Wingfield’s (2010) work in particular shows how emotions demarcate racial hierarchies in professional settings, as emotions like anger, pleasantness, and expressions of race-related fear form different sets of feeling rules for black professionals compared to their white counterparts. Harlow’s work on college professors finds that black professors experience the classroom differently as a result of the racial stigma that discredits them as professors. In this way, differences in social location within racial hierarchies shape the rules and norms surrounding emotion at the cultural level, which in turn shape individuals’ experience and management of emotion.

Emotions are conceptualized as resources that individuals access or fail to access or are the outcomes of stereotypes that construct racial minorities as out of place in professional spheres. Limited research, however, has looked at how “biographical structures and contexts”—themselves potentially shaped by social class and race—may in turn shape emotional experiences (Kusenbach and Loseke 2013:22). In linking emotion with risk, Lupton

calls for further research on “the ambivalences, contradictions and ambiguities of risk cultures and understandings” (2013:636). The current study addresses these concerns by looking at the overlap of emotion and the risk perceptions of participants in Phase I trials, situated within the conditions of racial and economic inequality in the United States. Qualitative in-depth interviews provide insights into the emotional dimensions of risk and the relationship between risk feelings and social conditions. We add to the field of social psychology by exploring how emotion and risk are socially configured and begin to address how biographical structures shape the experience of emotions and their use in justifying risky behavior.

METHODS

This article is based on 178 semi-structured interviews conducted with healthy volunteers as part of an ongoing longitudinal study of their participation in Phase I trials (see Edelblute and Fisher 2015 for details about the design of the larger study). As part of this larger study, we recruited individuals who were enrolled as healthy volunteers in a Phase I trial at seven clinics across the United States from May to December 2013. While our sample is not randomly generated, we sought a diverse sample of healthy volunteers by recruiting roughly equal numbers of participants from the Eastern, Midwestern, and Western regions of the United States. Additionally, we also included a diversity of clinic types in our sample, including one academic clinic, one pharmaceutical company clinic, one privately owned independent clinic, and four clinics that are part of contract research organizations. They varied in size dramatically, with one accommodating only 16 healthy volunteers to two having the capacity to house over 100 healthy volunteers at one time. All of the clinics

exclusively conduct Phase I clinical trials for the pharmaceutical industry.

At the outset of the project, we aimed to recruit from two clinics in each region of the country. One clinic in our sample housed only 9 healthy volunteers at the time of our visit, so we decided to add a third clinic from that region in order to more easily reach our recruitment goal of enrolling one-third of our sample from that region. We selected the seven clinics from approximately 40 such facilities because of their high volume of clinical trials and willingness to permit recruitment (as well as agreeing that they would not have access to our data). From a previous study on healthy volunteers (see Fisher 2015a, 2015b), we also knew that many healthy volunteers frequent multiple clinics, which provided us with “indirect access” (Monahan and Fisher 2015b) to a greater number of clinics through their experiences at those other facilities.

Phase I clinics tend to be located in large urban areas that are accessible by public transportation as part of these companies’ explicit strategy to quickly recruit large numbers of healthy volunteers (Fisher 2007, 2009). Our sample clinics followed this pattern and were located in large or medium cities in places that are generally accessible by car, train, or bus to a variety of populations. The identities of our clinics are confidential, but most were located in mixed-income areas, such as downtown areas, near large hospitals, or within more suburban industrial parks. These seven clinics, however, do not differ dramatically in their locations compared to other Phase I facilities in the United States.

Recruitment

All healthy volunteers participating in clinical trials at these clinics during our visits were eligible for our study. The

second author was part of each recruitment trip and typically had one or two other team members accompany her, including the first author or a graduate student. Each clinic varied in its organization, for example, housing healthy volunteers from different clinical trials in different units or having one large procedure area. Whenever possible, the principal investigator made a general announcement about who she and the other team members were, describing the longitudinal study and requesting that anyone interested in learning more approach one of the team members. During this announcement, she informed volunteers that the study was independent of the clinic and participation in our study was not required as part of their clinical trial participation and even confidential from the clinic. When a general announcement was not possible, team members circulated the unit and gave the same details about the study to smaller groups of healthy volunteers. Typically, within minutes of these announcements, the team had a list of healthy volunteers who were interested in learning more about the study. After the team had exhausted an initial list of prospective participants, individual team members would circulate to talk with other healthy volunteers to gauge their interest in joining the study. Healthy volunteers were informed that they would be compensated with a \$20 Visa gift card for participating in an initial interview and would have the opportunity to receive up to an additional \$450 for completing the entire three-year study.

Once a healthy volunteer was identified as potentially interested in the study, a team member met with him or her individually in a private room the clinic had allotted for our use. The team member initiated a more detailed discussion about the study and obtained informed consent from those interested in participating.

After the participant provided written consent, the team member requested that the person fill out contact and demographic forms. Once those were complete, the team member conducted an initial interview with the participant.

Roughly 90 percent of the healthy volunteers with whom we spoke enrolled in the study. At some facilities, we were able to talk to all healthy volunteers who were participating in a clinical trial at the time of our recruitment visit and invite them to enroll. At others, there were tens of healthy volunteers who were present, and we had a smaller target of participants to enroll. For example, one clinic had 9 healthy volunteers from which we recruited 8, while another had approximately 100 healthy volunteers from which we recruited 38. As a result, it is difficult to count the total number of healthy volunteers across the seven clinics from which we recruited our participants. The three notable instances in which we did not enroll the majority of healthy volunteers participating at those clinics would have had the effect of increasing the number of African Americans in our sample at one clinic, increasing the number of non-English-speaking Hispanics at a second clinic, and increasing the number of Japanese volunteers at a third clinic (the majority of these volunteers did not speak English and were not eligible for our study, as we did not have a team member who spoke Japanese). Nonetheless, our sample reflects the demographics of the overall pool of healthy volunteers at each of the clinics and is representative of U.S. healthy volunteers more generally (Fisher and Kalbaugh 2011).

The Sample

Based on the distribution of our participants' sex, race/ethnicity, and age (Table 1), our sample reflects the typical

Table 1. Demographics of Study Participants ($N = 178$)

	<i>n</i>	%
Female	47	26.4%
Male	131	73.6%
<i>Age</i>		
18–21	6	3.4%
22–29	34	19.1%
30–39	58	32.6%
40–49	54	30.3%
50+	26	14.6%
<i>Race/ethnicity</i>		
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%
<i>Foreign born</i>	35	19.7%
<i>Educational attainment</i>		
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%
<i>Employment status</i>		
Full-time	30	16.9%
Part-time	40	22.5%
Self-employed	48	27.0%
Not employed	58	32.6%
Retired	2	1.1%
<i>Household income</i>		
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%
<i>Clinical trial experience</i>		
1 study	38	21.3%
2–4 studies	49	27.5%
5–10 studies	45	25.3%
11–200 studies	46	25.8%

demographics of U.S. healthy volunteers found in previous studies of this population (Fisher 2015a, 2015b; Fisher and

Kalbaugh 2011). Specifically, our sample is predominantly men (74 percent) and racial and ethnic minorities (68 percent).

The breakdown of racial and ethnic groups for our participants was as follows: 40 percent self-identifying as black, 32 percent as non-Hispanic white, 21 percent as Hispanic, 7 percent as more than one race, and 6 percent as Asian, Native Hawaiian, Pacific Islander, or Native American. People who were born outside the United States make up 20 percent of the sample. The majority of participants (63 percent) were between the ages of 30 and 49, 22.5 percent were between the ages of 18 to 29, and 15 percent were 50 or older. Although most healthy volunteers are serial participants, we nonetheless were able to include in our sample participants with a wide range of Phase I trial experience, with approximately 21 percent participating in their first clinical trial, 28 percent enrolled in their second through fourth study, 25 percent enrolled in their fifth through tenth study, and 26 percent participating in more than 11 studies, with some reporting upward to 200 clinical trials.

As part of our interest in the factors that propel individuals to participate in Phase I trials, we collected demographic information about their education, employment status, and household income. About half of our sample received only a high school diploma or equivalent (such as a general education diploma, or GED), but 29 percent of the total had also reported taking some college classes. About a third received college degrees, with 12 percent holding associate's degrees, 18 percent holding bachelor's degrees, and 3 percent holding graduate degrees. Only 17 percent of our participants were employed full-time, about 23 percent had part-time work, 27 percent reported being self-employed (which for many included their participation in clinical trials), and 33 percent were not employed. Finally, participants' household income was distributed with 17 percent of our participants earning less than \$10,000, 29 percent between

\$10,000 and \$24,999, 39 percent between \$25,000 and \$49,999, and 14 percent at greater than \$50,000 per year.

Data Collection

The data presented in this article come from the first-round of interviews with participants. In-depth interviews allow us to examine how perceptions of risk relate to particular emotions as well as how biographical events and social structural positions shape configurations of risk, economic benefit, and emotion. Members of the research team conducted these interviews with each participant at a Phase I clinic while they were participating in a clinical trial. The interview guide was designed to solicit information from participants about their history of trial participation, perceptions of the risks and benefits of Phase I trials, factors influencing their decisions to participate in studies, experiences with the study staff and other participants as well as their confinement to the study facilities, and descriptions of their routine health behaviors.

Pertinent to the current article, we asked participants about their motives for participating in clinical trials ("What is your primary reason for participating in clinical trials?"); overall perceptions of the risks of clinical trials ("Based on all of your experiences participating in clinical trials to date, how risky do you think it is to enroll in studies like these? Why?"); and particular types of studies and procedures ("Which studies do you perceive to be riskier than others?" "In which types of studies do you prefer to participate?" "Which types of studies do you refuse to do?"). Our analysis focused on the answers to these questions as well as any references that participants made to their perceptions of the risks of clinical trials and related emotions throughout the interview. The length of the interviews varied primarily based on

participants' clinical trial history, but the average length was approximately 70 minutes, with a range of 21 to 164 minutes, and totaled over 200 hours of recorded data.

Data Analysis

All interviews were transcribed in full and de-identified by an independent transcription company. A research team member verified the accuracy of the transcript by comparing it to the original audio and made any corrections as needed. Next, we used Dedoose qualitative software for collaborative coding and analysis. Coding was a multistaged process that began with the development of a code structure based on several predefined variables—such as risk perceptions, benefit perceptions, decision-making factors, behaviors, and emotions—but additional codes, subcodes, and thematic memos were developed through a process of open coding (Miles and Huberman 1994).

Using the hallmarks of high-quality qualitative research, our process was based on the principles of “rich rigor,” transparency, and reflexivity rather than the principles of precision and replication that characterize quantitative research (Tracy 2010). Each transcript, once verified, was coded by at least two members of the project team (including but not limited to the original interviewer). A team member drafted a detailed memo for each transcript to encapsulate the major themes of the interview, including the participants' overall assessment of risk, level of experience with clinical trials, and perception of the benefits of participating in clinical trials. A second team member subsequently checked this memo and code applications for thoroughness and accuracy. When disagreement over a code or the contents of the memos arose, team members (including the principal investigator, a postdoc,

PhD student, and research assistant) discussed these issues at weekly meetings and routinely reflected upon the goals and assumptions of the project and best practices. The team developed and used standard operating procedures and an evolving code structure to document changes and expectations as the analysis progressed (available upon request from the second author). These were also shared and discussed with the project's co-investigators.

The theme of structural position as a motivation for Phase I participation emerged as the first author engaged in these coding steps. After discussing this with the team, a new thematic memo was created and applied to all relevant excerpts. Among these excerpts, those that also received codes related to risk and concurrent emotions were then isolated in the dataset and became the main focus. Parallel to analyzing these excerpts, the first author engaged with the literature on emotion and risk reviewed earlier in an abductive process that toggles back-and-forth between prior research and the data (Timmermans and Tavory 2012). Using Lupton's (2013) characterization of configurations of risk and emotion, we began to see patterns in how participants used their emotions to justify their risk perceptions as well as the role that biographical events played in this process. We then re-read participants' memos and transcripts to note how the relationship between risk and emotion related to biographical events and structural position.

Participants described a range of emotions related to their decision to participate in a Phase I trial, including desperation, terror, fear, gratitude, happiness, and relief. Similarly, a range of distinct contextual factors were referenced to explain how volunteers came to view the risks and benefits of clinical trials. These narratives often provided rich details on the biographies of participants, including

the situations that led them to accept the risk of a clinical trial. We divide the findings into two main themes: (1) financial need and configurations of emotion and risk and (2) the criminal justice system and configurations of emotion and risk. From participant reflections, we can begin to see how emotion and risk configurations emerge from social context and the structural conditions of class and racial inequality.

FINANCIAL NEED AND CONFIGURATIONS OF EMOTION AND RISK

Volunteers' decisions to participate in Phase I trials as well as their perceptions of the risks are shaped not only by their objective financial need but also by their feelings about their personal circumstances, including challenges such as insufficient income, mounting debt, chronic underemployment, and limited formal education. Such challenges are intimately linked to larger structural problems stemming from social inequalities, discrimination, and racism. Although individual circumstances vary, many healthy volunteers describe their entry into studies as catalyzed by their feelings of financial desperation, which they mobilize to justify their perception of the trial risks as inconsequential. This section illustrates how participants' emotions surrounding their financial situation shape not only the emotional responses they have to the risks and benefits of clinical trials but also the kinds of decisions they make about study enrollment. For poor and working-class volunteers, in particular, clinical trial risks can feel minimal compared to those in their everyday lives, including the risk associated with being unable to pay essential bills. In contrast, for more financially stable volunteers, trials that inspire more fear or worry are generally perceived as those that should be avoided.

Most of the healthy volunteers in our study spoke to us candidly about their financial troubles, often explicitly referencing their feelings of desperation and explaining how the study compensation could mitigate those negative circumstances. For example, Wanda, an African American woman, is a per diem nurse who struggles with the irregularity of her paychecks as hospitals have more or less need for an extra set of hands. She described her current situation:

So I was kind of like desperate; I got to pay my rent again. I haven't paid October rent, so when I get out of here, I'm going to have to pay October and November. So when I looked on the computer [for a study] . . . this one is for \$4,180. Yeah. So I just came and I screened for it because I urgently needed the money, you know?

Feelings of desperation were dominant throughout lower and working-class volunteers' description of why they participate in studies. Clinical trials are often a stopgap when participants' regular employment fails to make ends meet, while others rely on them for their sole source of income. Miles, an African American man, graduated from high school but has a sparse work history. Finding a Phase I clinic close to where he lives, he now participates exclusively at that clinic and considers it his full-time work. Justifying his choice to do so, he said, "Like anything to just make money . . . 'cause what if, you know, you're in the situation that you have to do this, and you don't have no choice but desperate measures and stuff like that." Such feelings signal both a material fact and feeling of entrapment and loss of agency (Blum 1996) that become part of the motivation to accept the potential risks of clinical trials.

For many healthy volunteers, the feelings associated with the opportunity to participate in clinical trials were used to partially explain their concerns about the risks of potential harm. Tina, a white woman with a high school education, has been participating in clinical trials for the past twenty years. At the time of her interview, she was participating in her first study in about seven years after having recently been fired from a food industry job. When asked about the overall risks of trials, Tina says, "You would hope that doing, participating in a study that you've only been dosed once or twice, that it won't lead to anything long-term. I think that is your biggest risk." She also shared her thoughts and feelings about enrolling in studies in spite of the risks:

When I was going to do a study, you know, I'd say, "It's just until, you know, I get another job. I need to get over the hump." 'Cause I was *devastated*, you know your money's cut in half; my rent was not [halved] or my gas bill. And I frankly found that *more terrifying* than whatever I was going to do during the trial. (emphasis added)

Like others, Tina weighs the risks of clinical trials in relation to risks of her current economic hardship. Unlike others, though, she expresses terror in relation to both the risks of medical testing and her financial need—an extreme emotion that conveys how seriously she views the risks of trials. Ultimately, the terror associated with her present financial needs and the certainty of trial compensation appear to outweigh the terror linked to uncertain immediate and future harms caused by investigational drugs. While this might appear as a rational calculation based on need, her ranking of terror in order to reach such a conclusion implies that emotion plays a primary

role in her risk configuration, while her current economic situation provides both emotional and material motivation to participate.

Perceptions of risk are indeed mutable based on a variety of factors, including individual participants' fluctuating economic stability and their emotional reflections on their present and past circumstances. Participants' financial status, however, also affects the *types* of risks they are willing to take as part of Phase I trials. For example, Jesse earns his income primarily from his participation in studies. He is a Hispanic man who "failed" out of community college after his first semester and also sells merchandise on eBay to supplement his study earnings. Although Jesse sees himself as more financially secure now that he is in his tenth study, he reflected on how his feelings about his economic stability have influenced his perceptions of the risks of studies:

[Initially] I guess the *desperation far outweighed the concerns*. You know, when someone's *desperate, like they are not even gonna think twice*, so I guess that's where I was at. I'm in a little better place now, so I'll think about it [the risk]. Like I'll try not to do any like schizophrenia [or] depression [clinical trials] 'cause then, you know, that'll mess with your mood. . . . When I first started being-, in 2012, like I was looking for anything. You know, I even did like spinal taps and stuff. Yeah. I've done three of them. And so I won't do those anymore though, just because I'm not as desperate as I once was. (emphasis added)

Jesse's narrative about his participation over time illustrates not only how configurations of emotion and risk are shaped by economic need but also how those configurations influence decisions about

study enrollment. The emotion of desperation appears not as simply an outcome of material conditions but also itself shapes the rational consideration of risks. With this and other participants in our study, less economic need (as less desperation) translates into more selectivity about the trials in which they enroll. In other words, participants' feelings of desperation stemming from financial need can close off or shape the cost-benefit calculus itself, leading to different decisions.

Beyond the decisions themselves, a participant's level of financial need shapes the emotions felt as part of the decision-making process. This is particularly striking with the small number of healthy volunteers who have large and stable incomes. Take, for example, Henry, who is a white, upper-middle class man who reports a household income of over \$100,000. He also describes his participation as financially driven, discussing particularly his motivation for supplemental income to help pay his children's private school tuition. Desperation is notably absent from his explanation, making way for other feelings about the risks of participation. Betraying some unease about participation, Henry often consults his wife, a nurse, and his father, a pharmacist, prior to signing his informed consent forms and avoids altogether any "crazy" studies that evoke fear:

So when I come and I sign the consent form and you're reading it before you go through the screening, that's when I really kind of look at it and can kind of tell, 'cause I mean there's some more serious drug testing out there with, you know, they put all kinds of *crazy things* in there. Up at [Clinic], they do a lot of the radioactive studies, things like that. *That's just kinda scary.* (emphasis added)

While he too describes himself as motivated by the financial compensation,

Henry openly acknowledges fear in association with particular studies such as radioactive ones. Although participants from all sociodemographic groups describe the importance of being informed and discriminating about trial participation, Henry justifies his decision to enroll only in lower risk studies as one influenced by an emotional reaction to some studies, the sense that they would expose him to "crazy" side effects. In contrast to his everyday—comparatively privileged—life, clinical trials can inspire an underlying fear that shapes his perception of the overall risk of participation.

Thus, financial need plays an important role in healthy volunteers' perceptions of the risks of clinical trials. This is not, however, just through a rational cost-benefit assessment. As these participants' perspectives highlight, their financial situations help to constitute the emotions they associate with both the risks and benefits of medical research. Feelings of desperation, terror, or fear may interweave healthy volunteers' perceptions of Phase I trials. Rather than a strict comparison of risks to benefits, risk emotions incorporate benefits and costs simultaneously and are compared to other risk emotions experienced in life.

THE CRIMINAL JUSTICE SYSTEM AND CONFIGURATIONS OF EMOTION AND RISK

In addition to economic opportunities, the criminal justice system emerged as an important contextual factor that shaped men's configurations of emotion and risk. When discussing clinical trial participation, healthy volunteers referenced three issues related to the criminal justice system: the threat of arrest in heavily policed neighborhoods, persistent economic and employment problems post-incarceration, and their personal involvement in illegal activities.

Threat of Arrest and Police

Participants varied in their openness about interactions with police and police presence in their neighborhoods. Philip, a biracial Hispanic man, commented: "In Brooklyn everyone's getting arrested for drugs and guns." Jamal, an unemployed African American in his early twenties, directly references the threat of arrest as a motivation to participate in studies:

From where I'm from, it's hard because a lot of people get arrested for, you know, crazy stuff. I-I live in Newark, so you get arrested for everything, drugs, all type of stuff. So why get arrested and people get arrested and go away for months and come back in the same position? I can go away for a couple weeks [for a clinical trial] and come back in a way better position. That's how I looked at it too.

Pointing to the threat of arrest in his city, Jamal sees the benefits of trials in relation to alternative paths rather than in relation to the risks. Having lived in heavily policed areas, Jamal sees arrest as almost inevitable, and this shapes his view of trials overall.

Martin, a biracial man in his late twenties, began his interview by noting that he is "from a hard place." Highlighting the police and race relations, he says:

[It's] a place where you know, north [and] south battle and [is the] capital of the Confederacy, that was Richmond, Virginia. So it's still going on, and they're not scared to show it, you know, the police and everything. I'm not saying I didn't- I didn't do things, but I'm not a bad person. I've always been a good person, but people were saying, "Oh, he got an excuse, and you got in trouble and blame it on people." It's not blaming it on people, man; I'm blaming it on the system

[laughs] and people need to realize that it's going on

Martin's account is somewhat cryptic, but clearly he sees police presence and race relations as a negative feature of his hometown. His description of police as being unafraid to show their Confederate roots seems to imply police brutality, harassment, or the threat of arrest directed at racial minorities.

Martin later contrasts clinical trials with the dangers—police and otherwise—of his neighborhoods:

I've been in different situations, so this little drug, *that's not gonna scare me more than what's going on out where in them places I've lived at*, so anything that happened to me or tried to happen to me. So, I don't fear, man, I don't fear drugs. I don't fear nothing out there. If it's my time to go, I'm going, you know? (emphasis added)

Martin uses the "places I've lived"—places notable for their police presence and racial unrest—as a foil to the risks of clinical trials. The risks detailed in an informed consent document are not the most salient risks to him, nor does he make a rational cost-benefit analysis. Instead, Martin uses a gradation of fear to explain his decision: The fear of trial drugs is compared with the fears he has experienced in heavily policed places. The criminal justice system, experienced through heightened police surveillance and the "trouble" he had, contextualizes trial risks and benefits.

Economic and Employment Problems Post-Incarceration

Individuals with a criminal record often face employment discrimination, making it difficult to obtain reliable and remunerative work (Pager 2008). Phase I clinics do

not perform background checks on perspective volunteers and can provide unparalleled financial compensation for such individuals. Benji, a 19-year old unemployed African American man, sees trials as “kind of good because, say, if there’s someone that actually has a record or something and it’s hard for them to get a job, and they’re actually healthy and they’re stressing and stuff, and they get a break pretty much.” Although he did not report a criminal record himself, Benji references the “break” that clinical trials can provide, which reveals both the economic benefit and the emotional relief of having an opportunity that is open to those individuals with a record.

Devlin, an unemployed African American man in his thirties with a history of incarceration, illustrates this theme as well. He discovered clinical trials in an employment guide and sees them as part of his “bigger plan,” though he would not give specifics. Upon learning that the study paid \$4,000, his first question was “Why not [participate]?” Later, after noting his experience being incarcerated, he says, “I’m in ‘heaven’ [in the clinic], you know what I’m saying, I’m relaxing and I am—no stress right now for fourteen days.” Stress—a likely outcome of his difficulty finding stable employment with a record—vanishes during his time in the clinic. In reflecting on the risks of studies, he says, “In general, I think there are risks, yeah, but [long pause] right now to me, there is no risk ‘cause I-I need this for my plan. . . . So I can’t afford to worry about risks.” For Devlin, trial risks are an afterthought to the financial issues that are likely linked to his criminal record. Here we see risk equated with the emotion of “worry” and framed as a luxury for those who can afford it.

Ray, an unemployed African American man in his early twenties, also referenced his personal history of incarceration: “When I came home from jail last year,

I decided not to go back to the streets. So therefore, I was like on the borderline of broke.” He described the difficulties that people trying to stay on a legal path can face:

But \$3,000 [from this study] is nothing, but it can give me a fresh start in life, you know. It takes money to make money as far as anything job-wise, period. You can’t go into a job looking like a bum. You know what I’m saying? You know, \$3,000 will help pay for a nice pair of clothes, nice dress shirt, going in sharp, smelling good, looking fresh.

Ray sees clinical trials as a means to a fresh start, compensating for the lack of resources and support that he needs to find employment post-incarceration.

Despite the positives of participation, though, Ray vacillates in his consideration of the risks of trials and where they might fit into his future. He says:

The health risk [of trial participation] is not worth it. But then again, at the same time, where I’m from, man, a lot of these men never even see 21 [years old]. So I don’t know, man. I might go seek out another one, another one [trial] again.

Ultimately, Ray draws on the same types of risks that contributed to his incarceration when he compares clinical trials to the shortened life expectancy that some experience in his neighborhood—a contrast that may lead him to return to trials for money despite his acknowledgment of the risks. Like Tina’s consideration of trials as less terrifying, Ray compares the health risks of trials to the risks of his neighborhood where men’s lives are often cut short. Direct references to emotions are absent from this excerpt, but the emotional appeal of a place where “men never even see 21” is telling.

Illegal Activities

Because some healthy volunteers have a history of engaging in illegal activities, the fact that clinical trials provide “legal money” directly shapes their configurations of risk and emotion. Here, feelings of desperation and fear, when present, are counterbalanced by these prior experiences. For example, Leroy is an African American man in his mid-twenties with a history of incarceration who did not finish high school. Despite his initial concerns about being judged by research staff, Leroy became “totally comfortable” with the trial risks along with a deep sense of gratitude to the staff who he found treat him much better than prison personnel did. Explicitly linking his affect toward studies to the risks involved, he asserted:

And to me, it's-, there's a little risk, but it's well worth it. Like it's not as risky as going to sell some drugs or robbing a bank, you know. So yeah, there's a little concern but not, not too much. I'm very willing and *happy* to-, it's a *blessing* to do it to me, to be here and be able to do this, so. (emphasis added)

Leroy's emotional responses to trial risks appear to link directly to his life conditions, whether or not he literally perceives these specific illegal activities as options. His criminal record limits his opportunities for work, and his decision to enroll in a clinical trial was framed against a series of difficult events, including expulsion from high school, being stabbed while on the job, and prolonged unemployment, as well as having three children to support. Although Leroy is currently working part-time, he says, “I needed a way that I could save up some money, basically, as fast as possible without it being illegal.” In this context, the lump sum payment of \$4,125 he was getting from the clinical trial became

something he was quite grateful to receive. Economic vulnerability may unexpectedly prioritize the emotion of gratitude over fear because he has experienced greater risks and has so few opportunities for material rewards.

Healthy volunteers interpret clinical trial risks through the frame of illegal activity as a way of making sense of them. For example, Philip, a biracial Hispanic man, talked about how his experience selling drugs have prepared him—with a little help from the criminal justice system—to channel his entrepreneurial ambitions into legal channels. After deciding community college was not for him, he opened a landscaping business instead and has used his clinical trial earnings as investment. Describing himself, he asserted:

I'm the type of individual that no matter where I am, I know how to make money. I'm still a hustler, you know, and I just converted my-. I told the judge that too, like you know, I was like, “Thank you for this [court-ordered] counseling because I just took my same hustler mentality and now I'm putting it towards something legal,” you know? Which this [clinical trial participation] is a hustle too, you know? You kind of have to be a hustler to be willing to do this too.

Within the worldviews of many healthy volunteers, earning an income through clinical trials appears similar to that of a hustle, positioned in “the grey world of the illicit and illegal” (Wacquant 1998:4) and characterized by an element of risk (see also Monahan and Fisher 2015a). By categorizing clinical trials as a hustle instead of a desperate act, Philip expresses gratitude (“Thank you for this. . .”) for the counseling that led him to legal routes to earn money, including clinical trials.

Marco, a biracial Hispanic man in his late twenties, also relies on past illegal

activities as a frame for configuring the risk emotions of clinical trials. He compared clinical trials explicitly to the risks of selling illegal drugs, a potentially lucrative and dangerous activity in which he engaged during his teenage years:

I do look at this [trial participation] as playing with fire. And you can only play with fire so long before you get burned. So, you know, that even goes back to when in my youth, my young youth or whatever, you know, hustling the streets, that's playing with fire, you know. I dipped in and dipped out. You know, that wasn't a career for me.

In contrast to Philip and Leroy, however, Marco was quite concerned about the risk of his first study, which is why he intends his trial participation to be temporary. In order to understand the risks of Phase I trials, he likens his participation to selling drugs, with its more familiar risks, using that frame to understand the dangers of pursuing either activity for too long.

The risks associated with the criminal justice system—including heavily policed neighborhoods, financial issues post-incarceration, and personal involvement in illegal activities—provide a frame of reference for healthy volunteers to consider the risks of Phase I participation. Participants may see trials as similarly risky to other hustles or as low-risk compared to the risks of illegal activities and their experiences of incarceration. Such constructions help them make sense of the unknown, and it is through this comparative process that their emotion and risk configurations emerge.

DISCUSSION

Our analysis of healthy volunteers used an emotion and risk configuration framework (Lupton 2013) to understand how

emotions overlap with risk perceptions and the role that social context and structural conditions play in these processes. Participants' reflections point to two main findings. First, economic need and experiences of the criminal justice system were two factors that appeared to contextualize participants' emotions and consideration of the risks of clinical trials. Various emotions, such as desperation, fear or terror, and gratitude, appear linked to participants' situated experiences of financial need and the threat or real consequences of incarceration. Assessing risk then is not a universal process, but based on the consideration of one's structural position and concomitant emotions, with one set of costs felt and weighed against other felt costs as well as one set of benefits felt and weighed against other viable benefits.

Second, emotions were not simply an output of these considerations but played an active role in their development and justification. Devlin illustrates this concisely with his articulation that he "can't afford to worry about the risks." Here, consideration of risk is bracketed as a luxury and seen, not as an intellectual consideration, but something one *feels*. The case of Tina highlights this as well. She considers risk in relation to other risk, but not in an intellectual fashion. Instead, she focuses on how these risks are *felt*, describing a ranking of terror as the process through which she comes to decide to participate in trials. Specific information on risks are rarely detailed in a dispassionate fashion but rather felt and embodied as they are described. Tina ultimately decides that one choice *feels* less terrifying than the other, not that one choice necessarily has greater risks than the other.

Financial need is, as we have shown, a dominant explanatory framework for participation in Phase I clinical trials, but participants' personal circumstances

are deeply influenced by and experienced as structural problems, including racial inequality. Racial minorities in the United States experience more difficulties securing and maintaining employment as well as find themselves excluded from jobs with better wages and benefits (Newman 2009). This is particularly true for African American men, who are more likely to face employment discrimination as well as heightened police surveillance than any other group (Alexander 2010). African American men also experience higher incarceration rates than any other group and have more difficulty finding employment and obtaining economic security post-incarceration (Pager 2008; Pager and Quillian 2005). This pattern might explain why in spite of the fact that participants of both genders and many racial and ethnic groups have a criminal record in our sample, no women and only minority men discuss clinical trial participation by contrasting it to the risks of incarceration and heavily policed neighborhoods. When individuals experience severe structural impediments (including racial discrimination) to how they can support themselves and their families, the risks of clinical trials are not isolated calculations but embedded in broader conditions of race and class. The broader economic and social factors that contribute to racial inequality may explain why minorities come to make up a disproportionately large percentage of U.S. healthy volunteers (Fisher and Kalbaugh 2011).

In addition to catalyzing Phase I participation, structural position, such as racial inequality, may also shape how emotions mediate perceptions of risks among minority healthy volunteers. Notably, risk emotions appear to vary based on the types of alternative sources of income and threats that participants have encountered in their lives. In this way, the results point to clear

“biographical structures” (Kusenbach and Loseke 2013:22) that help explain distinct configurations of risk and emotion across participants. Work by Wingfield (2010), Kang (2003), and Harlow (2003) focus on how feeling rules—expectations about how emotion is experienced and expressed—differ based on race. The present study builds on this past work by showing how configurations of risk emotions—emotions associated with a risky activity such as Phase I trials—are contextualized by social structure, most notably class-based and racial inequality.

While racially distinct emotional experiences are thought to derive from the stigma associated with a racial minority status (Harlow 2003), our findings suggest that class and race can also impact felt emotions through the different biographical events that shape comparative risks. Poor and working class participants draw on different life experiences that are often characterized by economic insecurity with its concomitant stressors as compared to participants with stable income. Likewise, our findings suggest that white, African American, and biracial participants use different comparative experiences in feeling the risks of clinical trials. For many low-income minority men, in particular, the real, or imagined threat of incarceration in their everyday lives provides a risk frame to contrast with clinical trials that is not as salient for women of any racial or ethnic group nor for white, non-Hispanic men. Thus, gender, particularly in terms of masculinity, may also be a key factor for understanding how configurations of emotion and risk are shaped by biographies. In experiencing the risks of clinical trials as emotions, degrees of worry or fear may be reserved for those whose class- and race-based status can “afford” them. Similarly, when the risks of clinical trials are situated in biographies that include (the

threat of) incarceration, they may evoke feelings of gratitude, ambivalence, or stress-relief.

Our analysis focused on how configurations of risk and emotion are contextualized by biographical events and structural position. It is based on unprompted descriptions of emotional responses to risk and, as a result, does not provide a comprehensive catalogue of all emotions felt in relation to the risks of Phase I trial participation nor can we make claims about precise causal relationships. Our sample, while not randomly generated, is demographically representative of the broader population of U.S. healthy volunteers (that is, predominantly men and racial minorities). This gives us reason to believe that our findings might be reflective of typical healthy volunteers who tend to enroll in clinical trials for the income they can gain from their participation. Our sample does not, however, reflect other types of research participants, such as those that might be participating in psychology experiments as college students or in marketing or focus group studies. Phase I clinical trial participation has been described as a subculture that is fairly unique from other research opportunities (Abadie 2010; Fisher 2015b), and our findings must be understood as such.

By situating healthy volunteers within their social context, the current analysis nonetheless highlights the structural conditions that shape configurations of emotion and risk in relation to clinical trials. Linked to the structural forces of class and race, participants calibrate feelings of risk in relation to their life circumstances. These findings develop our understanding of emotion and risk processes as co-constitutive and contextualized by comparative risk emotions. Through divergent biographies, participants can approach the same biomedical uncertainty and emerge with vastly different

feelings of and about risks. Healthy volunteers are not oblivious to or ignorant about the risks of Phase I clinical trials. Indeed, they acknowledge those risks, even underscoring the need to treat their trial participation as a temporary solution to improve their financial situation. In spite of this awareness, however, risk emotions are relative to the biographies of each participant as they contend with inequitable structural positions. In such a framework, those most structurally disadvantaged can come to feel not exploited or endangered but grateful for the economic opportunity to take on physical risks for the pharmaceutical industry.

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