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## Captive to the Clinic: Phase I Clinical Trials as Temporal Total Institutions

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### Abstract

This article develops the concept of *temporal total institutions* to describe how and why individuals voluntarily submit to highly-controlled and often dehumanizing environments. We focus empirically on Phase I clinical trials, which offer compensation to healthy people in exchange for testing investigational pharmaceuticals. Analyzing the experiences of 67 U.S. healthy volunteers, we illustrate how comparisons between Phase I trials and prison are salient to participants as they reflect on their confinement in research facilities and their interactions with other participants and research staff. We argue that conditions of contemporary economic insecurity and/or poverty facilitate the existence of coercive temporal total institutions by undermining voluntariness. Phase I clinics take advantage of the steady supply of individuals who will submit to the organization's demands out of hope that the income gained will be transformative for their lives.

### Keywords

Race; class; poverty; clinical trials; total institution; prison

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Phase I clinical trials are conducted on investigational drugs to evaluate their safety, determine an appropriate dosage range, and identify side effects. In order to achieve these goals, the studies are commonly designed to use so-called healthy volunteers as participants. These clinical trials also typically require the confinement of participants during the study, which can range from a few days to more than a month. Participants are paid for their time, with compensation varying primarily by the length of the study. Studies lasting several weeks typically pay several thousand dollars. Indeed, this compensation is cited as the only factor motivating healthy people to “volunteer” serially for Phase I trials, and this reliable base of repeat participants ensures the success of the research enterprise (Abadie 2010; Elliott 2008).

While the structure of Phase I trials differs dramatically from later-phase efficacy or therapeutic trials, there are also important demographic differences among participants that distinguish these studies. Medical researchers typically lament the difficulty of recruiting minority participants to clinical trials (e.g., Paskett et al. 2008; Shavers-Hornaday et al.

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1997), but Phase I trials enroll a disproportionate number of minorities (Fisher and Kalbaugh 2011). Specifically, Phase I participants in the U.S. are overwhelmingly represented by black men from low socio-economic positions (Fisher 2015; Cottingham and Fisher 2016). Healthy volunteers have been a largely understudied population, and researchers who have empirically examined these types of trial participants typically do not focus on the intersection of financial motivation to participate and the social context of profound racial and economic inequality in the U.S. (e.g., Grady et al. 2017; Kass et al. 2007).

Using interview data from a longitudinal study of healthy volunteers, we examine these individuals' experiences of being confined to research facilities during Phase I trials. We focus particularly on the participants who made unprompted comparisons between their time in the clinic to prison. To understand these comparisons, we draw upon Goffman's (1961) concept of the "total institution" and Scott's (2010) concept of the "reinventive institution," which shed analytic light on healthy volunteers' experiences *both within and outside* of the clinic. Classic conceptions of the total institution (e.g., prisons and mental health facilities) have garnered scholarly attention regarding the subjective experiences of those who live and work inside as well as how these institutions operate within broader contexts of social inequality. For instance, U.S. mass incarceration functions as both a generator and perpetuator of existing inequalities (Wakefield and Uggen 2010). In updating and reconceptualizing total institutions in an era of deinstitutionalization, especially for those with mental illness, Scott argues that total institutions have taken on a "reinventive" form in which members voluntarily submit, rather than being coerced, to their totalizing doctrines. Scott focuses on therapeutic clinics, utopian retreats, and academic "hothouses" to illustrate how reinventive institutions function, and these voluntary institutions appear to be places of privilege, designed for and utilized by those who have the resources to invest in themselves as a self-help or self-actualizing project.

To draw attention to how contemporary total institutions can be voluntary yet continue to exploit and exacerbate social inequalities, we use the case of Phase I clinics with their highly-controlled and often dehumanizing environments. We illustrate this case as a hybrid of repressively coercive total institutions and voluntarily self-actualizing reinventive institutions, what we call *temporal total institutions* to distinguish them from both Goffman's (1961) and Scott's (2010) conceptions. Unlike with reinventive institutions, the sociological puzzle is why people would voluntarily subject themselves (possibly serially) to an experience they explicitly perceive of as prison-like. We argue that conditions of contemporary economic insecurity and/or poverty facilitate the existence of coercive temporal total institutions by undermining voluntariness. Phase I clinics take advantage of the steady supply of individuals who will submit to the organization's demands out of hope that the income gained will be transformative for their lives.

## Phase I Clinical Trials as Total Institutions?

Phase I research has been conducted using confinement of research subjects since the inception of these clinical trials on healthy volunteers. In their initial instantiation in the 1960s, Phase I trials were integrated into prisons, with 85% of all such pharmaceutical trials being done on prisoners by the end of the 1970s (Bonham and Moreno 2008). Prisoners

were easily accessible and already confined in a controlled environment, and this research was thought to be a way for them to pay their debt to society (Hornblum 1998). While the prison was seen by pharmaceutical companies as an ideal environment to carry out Phase I trials, fallout in the early 1970s from the Tuskegee syphilis study directed scrutiny toward prisons as a site for medical research, leading ultimately to the prohibition of all non-therapeutic clinical trials in prisons (National Commission 1976 National Commission 1978).

With the elimination of prisons as a site for medical research, pharmaceutical companies had to look elsewhere for places to conduct Phase I trials. Many initially created “clinical pharmacology units” to test their drugs, but the dominant model today is to outsource these studies to commercial research clinics (Fisher 2009; Mirowski 2011). By shifting drug trials out of prisons, however, pharmaceutical companies had to incentivize participation by offering financial compensation, resulting in the enrollment of economically vulnerable populations, especially minorities. Because these individuals provide voluntary informed consent, the ethical issues associated with Phase I trials using healthy volunteers are assumed to be largely resolved.<sup>1</sup>

The convenience of prisons as ideal sites of Phase I research has continued in that the clinic spaces where pharmaceutical research is conducted in many ways mirror prison environments and have many of the same constraints of incarceration. Healthy volunteers have all their belongings searched on admission for contraband, often are required to wear scrubs, are literally locked into the clinic space, and must comply with strict schedules for eating, sleeping, and medical procedures. Unlike prison, however, healthy volunteers can discontinue their participation at any point in the study (and thereby forfeit some portion of their compensation).

One frame for understanding the lived experience of Phase I trials is to consider them, like prisons, as “total institutions.” Erving Goffman (1961) defined total institutions as “place[s] of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable amount of time, together lead an enclosed, formally administered round of life” (p.xiii). He argued that total institutions share four common characteristics: (1) life is conducted in the same place under the same authority, (2) daily life within these institutions is carried on in the immediate company of others, (3) all phases of activity are tightly scheduled, and (4) the various enforced activities are brought together into a single rational plan purportedly to fulfill the official aims of the institution (Goffman 1961:6). For Goffman, prisons epitomize total institutions, and prison-like places can be dehumanizing to those who are captive in them.

Phase I trials have features consistent with Goffman’s conception of total institutions. Specifically, Phase I trials are (1) conducted in the same place (specialized clinics), (2) carried out in the immediate company of others (participants who form study “cohorts” or

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<sup>1</sup>The amount of compensation for study participation often continues to be a thorny ethical issue (VanderWalde and Kurzban 2011). The problem is that should researchers pay too much, it would be considered “undue inducement” (Wilkinson and Moore 1997). If, however, they pay too little, there are concerns about exploitation (Phillips 2011). We have argued elsewhere that there are important ethical issues in Phase I trials beyond those of compensation amounts (Walker, Cottingham, and Fisher 2018).

“panels”), (3) are tightly scheduled (having highly structured protocols for drug dosing and medical procedures), and (4) are designed to fulfill the aim of the institution (drug development). However, Phase I trials can be said to differ from Goffman’s conception of total institutions because participation in such studies is both short-term and voluntary. As a result, it may be counterintuitive to think of Phase I trials as total institutions because no one is compelling individuals to enroll. Yet, the view of Phase I participation as *merely* voluntary ignores the structural conditions and social inequalities that make some groups of individuals more likely to turn to medical research as a mechanism to earn income (Fisher 2013).

Goffman’s work on total institutions has been criticized because it does not sufficiently problematize power and social control (Ritzer 2004; Scott 2011). Specifically, his conception of the prison as a total institution ignores subtler forms of power and discipline because he focuses on only brick and mortar aspects of the institution (Giddens 1991). In contrast, Susie Scott (2010) theorizes the “reinventive” characteristics of total institutions, or “places to which people retreat for periods of intense self-reflection, education, enrichment and reform, but under their own volition, in pursuit of ‘self-improvement’” (Scott 2010, p. 218). Scott’s examples are often of relatively privileged members of society who have the time and resources to work on themselves, but reinventive institutions nonetheless have profoundly coercive elements enacted through disciplinary regimes. In particular, Scott argues that as they seek to transform themselves, individuals alter their identities in relation to these institutions, embrace the rules and activities required of them, and become indoctrinated into a homogenizing culture of belonging. In other words, Scott accounts for agency in her conception of these institutions while at the same time attending to the subtler forms of power to which individuals submit. Membership has the appearance of choice and freedom, yet often involves intensive surveillance and indirect forms of coercion (Scott 2010, 2011).

Bridging existing scholarship on total institutions with our research on Phase I trials, we suggest that these trials function as “temporal total institutions” that are at times total in the Goffmanian sense but include new instantiations of coercion and control. Recognizing the tension between voluntariness and coercion in Phase I trials, the addition of a temporal dimension to conceptions of total institutions accommodates for voluntary consent to conditions of control as the very terms of the exchange. Indeed, while consent is revocable, the conditions of participation are non-negotiable and, at times, dehumanizing. Moreover, the payment that motivates participation also demands completion of the clinical trial. Discontinuing a study means forfeiting a sizeable portion of the compensation that is reserved as a “completion bonus.” This payment structure helps to ensure that pharmaceutical companies get the data they are paying for by penalizing those participants who exercise their right to withdraw from the study. Additionally, temporal total institutions can encourage voluntary participation through the “reinventive” promise of the compensation, wherein individuals see clinical trials as a way to better their circumstances (see below and also Cottingham and Fisher 2016). Unlike reinventive institutions, however, it is not the institution’s doctrine that is the source of transformation. Participants neither have to subscribe to the ideology of the Phase I industry nor see the time itself in the clinics as meaningful. They are not trying to better themselves as individuals, but instead they seek

to improve their lives through increased cash flow. In other words, the promise of reinvention is through the exchange itself, the financial compensation participants will get by fully submitting to the needs of the institution.

Importantly, the concept of a temporal total institution provides an analytic lens on the relationship between total institutions and structural forms of inequality. Because there is markedly less known about contemporary organizations that fall outside of the purview of Goffman's vision of the total institution, there is less sociological attention directed to how and why some individuals in society are more likely to submit voluntarily to totalizing conditions of control. In the case of Phase I trials, demographic evidence indicates the effects of broader social inequalities on the participation of healthy volunteers. Given the overwhelming representation of the poor and African Americans in U.S. Phase I research, these trials can be said to exist within a racialized social system (Bonilla-Silva 1997), meaning a system that is hierarchically stratified to afford economic and employment privileges to some and disadvantages to others. Many blacks and racial minorities find themselves caught in the web of structural disadvantages, especially when considering that black males (particularly those without a high school education) are disproportionately more likely to be imprisoned (Alexander 2012; Pettit 2012), and this imprisonment leads to even bleaker economic prospects (Pager 2008; Western and Pettit 2005). With this broad context in mind, Phase I trials, as temporal total institutions, are situated within and exploit conditions of racial and economic inequality by undermining voluntariness in the recruitment and retention of healthy volunteers. Our findings illustrate how the racial and economic insecurity of participants makes healthy volunteers more willing to be subjected to what they often perceive as the prison-like conditions of the clinic.

## Data and Methods

Data for this article come from a larger longitudinal study of healthy volunteers' participation in clinical trials, which enrolled 180 healthy volunteers at seven different Phase I clinics across the U.S. (see Edelblute and Fisher 2015). As part of the longitudinal design of the study, participants were randomized using a 4:1 ratio to one of two arms: "full participation" or "control." Healthy volunteers who were allocated to the full-participation arm participated in five semi-structured interviews over the course of their three-year involvement in the study. The first interview took place face-to-face upon enrollment, and subsequent interviews occurred by telephone at six months, one year, two years, and three years from enrollment. Participants in the control arm of the study were interviewed only at enrollment and again three years later, with the goal of using this group to evaluate whether our study had any effect on the full-participation arm. Participants were paid for their continued involvement in our study, with those in the full-participation arm receiving up to \$470 and those in the control arm up to \$220 over the course of three years.

The healthy volunteers in our study represented the diversity of U.S. Phase I participants. As noted in previous studies (Fisher and Kalbaugh 2011; Grady et al. 2017), healthy volunteers tend to be lower-income, minority men. Our sample reflected these trends with 73.6% of our participants being men and 68.0% being members of minority groups (40.4% black; 21.3% Hispanic) (see Table 1). Additionally, the majority of our participants were under- or

unemployed, with only 25.3% holding full-time jobs or running their own businesses. As is typical, most of our participants were not new to clinical trials: 21.3% were in their first study, 27.5% were in their second through fourth, 25.3% were in their fifth through tenth, and 25.8% had participated in eleven or more studies.

The data for this article are drawn from the 440 semi-structured interviews that took place with all participants at enrollment (“baseline”) (n = 178) and the full-participation group at six months (n = 131) and one year (n = 131).<sup>2</sup> As part of their interviews, healthy volunteers were asked to reflect on their experiences participating in Phase I trials, their perceptions of the risks and benefits, their decisions about what studies they preferred or wanted to avoid, as well as questions about their financial situations. All interviews were transcribed before being coded by at least two members of the research team using qualitative analysis software. The second coder’s task was to ensure completeness of code applications so it was not performed independently (i.e., the second coder could see and edit the first coder’s codes). We did not ask questions in these interviews about how Phase I trials were like prison, but we anticipated this theme from preliminary research on this population and coded all participants’ references to studies being like prison, jail, “locked up,” and so on. As part of subsequent analysis, excerpts receiving this code were then grouped into more specific descriptive categories, including the prison-like conditions of the clinic and interpersonal interactions. We also noted instances in which respondents expressed ambivalence about the comparison between the clinic and prison.

Included in this article are the data that emerged unprompted from respondents who compared the clinic to prison. In total, 67 healthy volunteers, 37.6% of all participants in our study, used a prison analogy when describing Phase I trials. These comparisons included explicit discussions about how the clinic was similar to and different from prison. The high prevalence of this unprompted theme underscored the importance of the prison comparison as part of healthy volunteers’ experiences. As Table 1 indicates, the participants who compared the clinic experience to prison were representative of our entire sample when it came to their gender, race, ethnicity, household income, and educational attainment. Where the sub-group of participants differs from the sample as a whole is by their experience participating in clinical trials, their age, and employment status. Specifically, first-time participants were far less likely to compare the clinic to prison, which might be a function of interview timing because some with first-time participants were conducted prior to them ever spending a night in the clinic. It is also noteworthy that participants in their 30s were much more likely to compare the clinic to prison, especially compared to participants over 40, but it is less clear why age would have this effect. We also found that unemployed participants were more likely to make the comparison with prison than were those with full- or part-time work. Without another source of personal income, these participants might be all the more likely to feel the constraints of the clinic. This is a theme we further explore below in the analysis of our findings. Because these were unprompted comments, we cannot

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<sup>2</sup>We withdrew two participants from our study when it was discovered that the same person enrolled twice, giving us different data. We disregarded all data collected from this person, including demographic data; this left our sample at 178 participants, with 144 in the full-participation arm and 34 participants in the control arm. For follow-up with the full-participation arm, 13 participants either voluntarily withdrew (n = 3) or were lost to follow-up between enrollment and their six-month interview (n = 10). We retained the remaining participants (91%) and successfully conducted 6-month and 1-year interviews with them.

know how the remaining healthy volunteers in our sample would compare the clinic to prison if asked; they might not perceive Phase I trials as any less constraining but simply did not use the prison analogy to describe their experiences. As we discuss our findings, we use pseudonyms for our participants and flag the gender, race/ethnicity, and clinical trial experience for each person. All participants quoted are not employed unless otherwise noted. Detailed demographic information about these participants can be found in the Appendix.

## Comparisons of the Phase I Clinic to Prison

Participants' reflections on the clinic space through comparisons to prison reflect the ways in which Phase I trials operate as, what we call, temporal total institutions. We illustrate that in spite of the technically voluntary nature of Phase I trials, healthy volunteers' experiences of the clinic as prison-like reveal the extent to which once admitted to the clinic, participants must submit to conditions of confinement and control as the very terms of the exchange. Specifically, we examine how healthy volunteers use prison analogies to describe study confinement and the material conditions of the clinic, including their experiences of other participants and research staff. We also explore a parallel narrative in which healthy volunteers describe Phase I trials as *unlike* prison because they have the potential to positively transform their lives. In both types of unprompted comparisons to prison, healthy volunteers are reflecting on their experiences of the power dynamics within the clinic through narratives of coercion, dehumanization, and choice. When combined with an analysis of the larger societal forces that shape cycles of participation and undermine voluntariness, these experiences provide evidence of temporal total institutions to which minorities and the poor are subjected.

## Managing the Clinic Confinement

One of the main reasons that healthy volunteers likened their experience to prison is the confinement requirement associated with most Phase I trials. The purpose of the confinement period is to control factors—such as foods, beverages, tobacco, alcohol, and so on—that might affect the results of the studies. Participants generally understand this goal, and they acknowledge that the study compensation is based on the length of time they must spend in the facility, which makes longer confinement periods financially desirable for many. Regardless, once they check in for a study, trial participants are like the inmates in Goffman's (1961) typology of total institutions because they lose access to the world outside the clinic and must adhere to all the rules dictated by the facility and the study protocols. The presumed voluntariness of their time in the clinic is often undermined by their economic need, making them more captive to the clinic than might be expected.

Participants from diverse demographic backgrounds asserted that being locked into a Phase I clinic is similar to being in jail. For example, Owen, a black man who worked full-time and was in his fourth clinical trial, joked, "It's just like it make you feel like jail a little bit. I ain't never been, but it make you feel like you in jail, and you got to eat when they tell you to eat, you know, so they mess with you a little bit" (baseline). Likewise, Sherrie, a white woman who worked full-time and was a second-time participant, explained, "I kind of feel like we're in prison. I mean, I'm sure it's much worse in prison... but, still, I get a kind of

feeling what it's like to have your freedom taken away from you" (baseline). Both Owen and Sherrie have enrolled in studies to help make ends meet with tight family budgets, and while their time in the clinic was uncomfortable, they deemed it worthwhile for their families.

For white participants, in particular, the experience of being in the minority when confined also brings out racialized interpretations of the parallel between clinical trials and prison. Charlie, a white man, who had unsteady income from acting but regular income from approximately 60 clinical trials over 20 years, reflected,

Studies are like quite a sociological phenomenon. I mean, I used to look around at some point sometimes during studies, and I would be like, you know, if someone didn't know who we were or what was going on and they just took a photo of all of us in our scrubs... you would think it was almost a mental home or something, a halfway house, you know, or a prison even. You'd think it was a prison maybe. You know, it was a lot of black guys. It's a lot of guys, some guys are pretty rugged... I'd sit there and look at this phenomenon. (6-months)

In addition to acting, Charlie had a history of unstable employment that rarely covered the bills or lasted long enough to leave studies behind. Despite demographic differences, many participants experienced Phase I trials in terms of feeling a loss of freedom, having one's activities controlled, or being in close quarters with racial or ethnic others.

The complaint that study confinement feels like prison was incorporated into how participants prepared to go into the clinic. For example, Paolo, a Latino man who had enrolled in 20 studies, described his process for dealing with the confinement period:

You got to go into the place as if you're serving time. So, when you serve time, you're going to do two things: you go in the yard and work out or... go to the library and go read. If you go into a place like that and you just don't acknowledge that things are going to be taken away from you, then you're not going to do well when you come out. You won't. In the long-term, you won't. So, and now when I go inside, I sort of get in my mind to like finishing a book or getting a certain subject into me... so by the time I come out, I don't feel like anything is really missed, anything is passed. (6-months)

As someone who had spent time in jail, Paolo borrowed from that experience to find ways to handle confinement despite study participation being a technically voluntary endeavor. Moreover, when Paolo's overall economic insecurity is taken into consideration, it becomes clear that the constraints extend beyond the clinic space. When asked what the initial catalyst was for getting involved in studies, Paolo described his situation in this way: "Unemployment. I remember it was with a friend that I'm not friends with now... We were around 23, around there? We were circumstances of our environment, living in the hood, living in the ghetto" (baseline). Remarkably, Paolo's description of why he began participating in clinical trials could also serve as an explanation for how he found himself incarcerated. Persistent unemployment and neighborhood context are broader forces that are critical factors in both types of experiences.



Managing the confinement period, however, does not equate to enjoying it. Even if healthy volunteers can technically handle their time locked in the clinic, it can still be a negative experience. For example, Everett, a black man who had participated in 24 clinical trials, told of his experience in one particularly long study:

The longest I ever been to, just like in [total] days, has been 35. ... 30 to 35 days is my longest. My family can't take it. I-I go stir crazy. I can't take it. It's like being locked up. Especially if it's a place that doesn't have many things for you to do... Made a lot of money in that study. Don't get me wrong... Made good money. (baseline)

Like prison, confinement in clinical trials is not only hard on the participants but also on their families. In Everett's case, he was leaving his wife and three children for more than a month as part of the trial. In the end, he and other participants can justify it in terms of the compensation they receive, but that does not change the difficulty of the experience itself. To put his choice to participate in context, Everett described his financial situation as "erratic" and a stringing together of government support, irregular employment, and trials; even with all these streams of income, Everett still bemoaned, "Believe it or not, it's still not enough" (baseline).

The limits to the voluntariness of Phase I trials comes into sharp relief when healthy volunteers are confronted with personal situations outside of the clinic while they are confined during a study. For example, Darius was a black man who had participated in more than ten clinical trials and also found odd jobs between studies. He, his partner, and seven children lived on the West Coast, but he traveled to Phase I clinics across the country to enroll in studies. During his initial interview, he talked about his three-year-old son's severe asthma for which he had been hospitalized several times. Darius shared his worry about traveling for studies given his child's health condition:

There was one incident [when] I was out of town, and he was rushed to the hospital. ... And it was one of the scenarios where I was way across the country, and then he's at the hospital, and then he wasn't really looking too good. ... So I did a lot of praying, then overnight he got a lot better. 'Cause I was gonna have to leave the study and get back home, but things turned out good... That's the negative things that goes through your mind when you're somewhere and you're doing a study, the worst-case scenario, you're gonna have to leave [the study] for a family emergency and all that, then you basically just threw a lot of money away. So that's-that's the things I pray for: that that never happens when I'm gone doing a study, so I don't have to leave. (baseline)

Clinical trials were the primary source of income for Darius' family, so there is tension surrounding whether a situation at home warrants withdrawing from a study. Coupling his financial situation with his worry about his son, it is not difficult to imagine that the clinic can feel like prison, a sentence that needs to be served in full in order to receive the compensation.

The participants who compared Phase I trials to prison because of the confinement in the clinic reveal two things: the material constraints of trial participation and the broader

economic constraints that motivate participation in the first place. These participants ranged from people who financially relied wholly on trials to those who used it as an occasional supplement. They used money from trials for emergencies, to pay rent and other critical bills, or to enjoy a sense of economic mobility, among other things. Thus, confinement in the clinic is all the more constraining because economic need compels people to volunteer.

### Experiences of the Clinic Facilities

In addition to confinement, participants noted several other characteristics of Phase I clinics that made their study participation feel like a prison experience, such as the clinic space, fear of other participants, and their interactions with the research staff. While the limitations to personal freedom might be a necessary part of Phase I trials, it is more difficult to see why the clinic conditions should be reminiscent of prison. Importantly, subpar facilities signaled to healthy volunteers that the clinic staff did not appreciate or respect their needs or even value them as individuals. Participants' experiences of the clinic can be read analytically as the dehumanization that is designed into the structure and routines of total institutions (Goffman 1961; see also Malacrida 2005).

While clinics can vary in how their spaces are configured, healthy volunteers often found that many facilities were designed primarily to house as many participants as possible rather than for those participants' comfort. For example, Darius described one such facility:

They treat you like crap over there... their demeanor, like they act like you're-, you feel like you're in jail or something like that. And then the way they put you up: you're in a room, so it's like 15 bunk beds with a bunch of people in there, and it's like 15 dudes in one room, and it's just, you know, it's-it's not cool. And you got different personalities in there, and... the place is small. It's like cramped.  
(baseline)

These conditions were a surprise to participants who, not knowing what to expect, assumed that the clinics would resemble hospitals, with semi-private rooms and individual bathrooms. While some Phase I clinics are indeed organized in this way, it is not the most common spatial design. Bunk beds and communal bathrooms are much more typical in these facilities. Sally, a white first-time participant who was unemployed and recently evicted from her apartment, joined a clinical trial to get enough money to rent a new place for her and her son. When confronted with such a space, she reflected on clinic conditions this way:

I expected the rooms to be like [the way they were for] the very first screening—like when they took our ECG's or whatever at first and did whatever—where we had like a hospital thing and the curtain that pulled around, you know. I-I expected that. And then [when I checked in for the study,] I saw these [bunk] beds out here, and then I was like, "Shit!" So then I was like, and I was like, "Uh, uh uh... all of us together [wearing our tan scrubs], we look like a box of Band-Aids." It is kind of, you know, prison-y. You know, the showers without the door, you know, just kinda weird. (baseline)

Finding the clinic to be oddly like prison, she balks at being forced to wear scrubs, which is another common frustration expressed by participants.

While not always explicit, clinic conditions are experienced as dehumanizing by many participants. There is often the sense that the clinics can and should do better in how they treat participants. For example, Morgan, a white man who had participated in 15 studies, complained,

Every time I've ever done a study there, I always complain about the food, and I know other people do the same thing. Figure maybe one day they'll get the message but they haven't... And if you got people cooped up for sometimes a few days or sometimes a week or [even] weeks or a month, the food ought to be a little better... You're sacrificing a lot of your time; you know, you ought to be fed better than a prison inmate. (baseline)

Morgan used a comparison to prison to assert that the clinic conditions are unacceptable given the "sacrifice" healthy volunteers make by enrolling in studies (see also Monahan and Fisher 2015).

In addition to physical manifestations of the clinic, healthy volunteers also describe fears they have about other participants as contributing to their feeling that being in studies is like being in prison. In fact, many make assumptions about others, claiming that those who act like "prisoners" are likely people who have a criminal background. It is true that Phase I clinics typically do not run background checks on healthy volunteers. On one hand, this means that there is no discrimination for entry into studies based on individuals' histories of incarceration. This is a positive for many participants because it provides an economic opportunity that many individuals would not otherwise have (see also Cottingham and Fisher 2016). On the other, it also creates some level of fear and distrust of participants who are assumed to be ex-convicts and are seen as suspect and potentially dangerous. For example, Rafael, a black Hispanic participant who was in his twentieth study and described himself as a "little gay guy," described participants this way:

You don't know who you're going to run into [in studies]. You don't know what type of people they are... Like people, like I said, here are coming out of jail, so these could be ex-cons, ex-murderers, who knows, thieves or whatever. I'm like a little cautious. (baseline)

This sort of fear of other participants was quite common. In part, this was a result of how some clinics are set up. For instance, Rafael reflected on the presence of metal detectors at the clinic:

Okay, I've never been to a study place where they had metal detectors [other than this one]. So that, to me, is another strike [against this clinic]. Like this is the hood, this is people getting out of jail, probably trying to sneak in shanks... They even wanded me down, you know, like metal detector wand. (baseline)

This particular clinic's use of metal detectors gave Rafael the idea that there might be a reason to fear, and to his mind, the people to fear were those who were straight out of jail. Another example of being afraid of sharing the clinic space with formerly incarcerated people came from Sherrie when she declared,

I'm assuming they let felons in because they've said before that—the staff has said before—that they worry sometimes because they have rapists that are there, you know, convicted rapists who stay the night. And they put us all in the same room together, men and women... One night there was a girl who worked there, and she... was afraid to open the window [to the nurses' station] when the guys came up. [incredulously] But you don't mind putting the participants in bedrooms with these men, but you won't even open the window at night to ask them what question they have and you're behind a locked door?! You know what I mean? I think that it is wrong because, "Oh, I'm gonna protect myself, but you guys don't count because you're just lab rats, so it doesn't matter. You signed up for this so you're asking for it," basically is what I feel like [they're saying]. (1-year)

Healthy volunteers like Sherrie expressed these anxieties perhaps because they felt vulnerable being locked into the clinic space with participants who are unknown and different from them. These respondents illustrated that it is not just the material conditions of the clinic but also their interactions with and assumptions about other healthy volunteers that made the experience feel like prison. Whether they were worried about direct threats to themselves or were describing a type of attitude that some participants might have had, there was nonetheless a strong belief that some healthy volunteers were criminals and needed to be avoided.

In spite of all the observations that healthy volunteers made about the clinic space and other participants, it was their interactions with staff that made explicit how prison-like conditions were dehumanizing. Sherrie's quote about the staff member safely locked in the nurses' station while rapists might roam the clinic was one articulation of why participants felt as though the staff saw them as inferior. Concerns like these were often explicitly tied to participants' perception that the clinic is like prison. Travis, a black man who had enrolled in about fifty studies but had slowed down his participation over the past several years, speculated:

I think they treat us all the same based on whatever happened prior [with other participants]. So if they had bad things that happened, then it's, "[bitterly enthusiastic] Ooh, let's lock 'em down the next go around. These people that just walked in... let's lock 'em down! Let's clamp on 'em! Let's be real militant-like." You know, it's like, "Come on!" I mean, [exasperated] this is research! You know, I'm not in jail! (1-year)

Travis was aware that participants could cause problems during studies, but he took issue with the research staff treating all participants as if they were unruly inmates needing to be subdued.

Many healthy volunteers tried to make sense of the dehumanizing treatment they claimed to receive from the staff by focusing on the compensation. Natasha, a white immigrant to the U.S. and a full-time study participant who had enrolled in 45 clinical trials, commented,

They were rude! You know, and I was like, "You don't talk to me like this. I'm just as human being as you are." Just because I'm [a] subject there and I make more money than you do, it doesn't mean that you have to treat me like I'm some,

something... Some of them are really good people, but some of them are not. Some of them treat you just as a number, as a subject, not as a human being. Either they're jealous or they just, I don't know, you know... we make more money than they do, so they don't like us. (1-year)

Natasha, as well as others in our sample, believed that they were treated badly because they were paid well in Phase I trials. While it is unlikely that healthy volunteers actually make more money annually from clinical trials than staff make, this was nevertheless a strong narrative among participants because they focused on the amount they got for their time in the clinic compared to staff for those same number of days.

Regardless of the veracity of their interpretation for why staff might treat healthy volunteers with disrespect, it was also another window into the economic need that motivated participants to enroll in clinical trials. The financial exchange was also what prompted them to return to the clinic in spite of feeling that it was like prison. For example, Zach, a white struggling musician who had participated in six studies, admitted,

When you're in the middle of a study, there's always that, "Oh God, like I'm doing this again. It's rough. I gotta stay in here like I'm in jail, eat bad food..." Every time you're in a study, you don't want to do another one. I mean, but it goes away when you get out. (1-year)

When reflecting on his overall thoughts about participating in clinical trials in the same interview, Zach said, "They're paying me a lot of money, and so I don't mind." The financial motivation was really at the heart of participants' perceptions, not just about the confinement but also about all the conditions to which they are subjected.

Participants' accounts of being treated like prisoners—or "cattle" and "lab rats," in some instances—and their discomfort about the physical environment and routine of the clinic, in others, can be thought of as manifestations of a total institution experience. Whereas the confinement itself challenges participants' sense of voluntariness, the clinic conditions are experienced as similar to prison because of the felt constraints in terms of what participants must wear and eat and because of the dehumanizing effects that these structures and their interactions with staff can have on them. For Goffman (1961), a central theme of the total institution is the staff–inmate relationship, one that he considered to be fundamentally antagonistic. These antagonisms arose from a fundamental difference in position within the clinic. Research staff were closely aligned to the institutional goals of the clinic, and as participants' statements about the clinic revealed, inmates were on the receiving end of the institutional goals of the clinic carried out by staff. Thus, the temporal total institution is not merely temporary consent to confinement, but also immersion into a set of practices and meaning between staff and participants that many participants experienced as dehumanizing.

### **Clinical Trials as Transformative**

As healthy volunteers compared their experiences in Phase I trials to prison, sometimes the salient point of comparison was how the clinic was *different* from prison. These negative comparisons, often made by the very same participants, also perform important analytic work. Specifically, contrasts with prison represent how Phase I trials as a temporal total

institution can be a place where their short-term investment of time in the clinic could be transformative in the long-term. That these trials rarely have this impact on individuals' lives can also motivate their serial return to the clinic with the hope that the next time will be different. This conception of total institutions complicates further the blurring of voluntariness and coercion because the unfulfilled promise of transformation is experienced as a temporary constraint that must be endured without complaint because it is a path to future freedom and financial benefit.

The fact that Phase I trials pay relatively well was often the first reason that healthy volunteers gave to explain how participation differs from prison. For example, Derek, a black participant in his second study, rehearsed this view when he said, "All I do is just give them my time. I get into a regulated facility. You could say it's like jail, but people in jail don't even get paid to be in jail" (6-months).<sup>3</sup> The controlled nature of the clinic itself reminded Derek enough of prison that he made the comparison even as he refuted it based on the payment he would receive for his time there. Similarly, Elena, a Hispanic participant in her third study, reflected this way: "But then this other guy [said], 'No, it feels like prison in here.' And I go, 'I don't know about that... ain't nobody going to get shanked here'" (baseline). She went on to describe the little freedoms, like watching TV and interacting with other participants, as distinguishing the clinic from prison, emphasizing that healthy volunteers do not actually pose a threat to each other. In general, she focused instead on the positive impact of studies in her life, saying,

[Participating in clinical trials] is a way to keep me just a little bit above water, keep me from sinking... in every aspect that I can think of, I mean, [this clinic] is helping me a lot, you know, to go ahead and clothe my children, to go ahead and pay bills. (baseline)

Thus, for Derek and Elena, the clinic could not be like jail because it was the institution that was keeping them financially afloat, which was particularly important given that neither of them was employed. In spite of the different framing of the clinical experience, their dependence on studies highlights critical constraints even if not felt within the clinic. Much like their counterparts who saw the clinic as a prison, their perceptions were also shaped by their economic insecurity.

Additionally, those who contrasted Phase I trials to prison often focused on the fact that healthy volunteers had the choice about how to experience their time in the clinic. They could focus on the money and the positive things that it could do, or they could focus on the temporary negative aspects of the confinement. For example, Austin, a black man, was working part-time and had participated in three studies at baseline, but he ended up quitting that job by the time of his 6-month interview and reported enrolling in six additional studies in that time frame. Thinking about the right attitude for clinical trials, he emphasized,

You got to really like put yourself into like the state of mind like... where you just focus on your next [study] paycheck, you know, and focus on all the positive stuff

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<sup>3</sup>Prisoners do, however, typically receive a very small monthly income in exchange for work. See <http://www.prisonpolicy.org/prisonindex/prisonlabor.html>

you're going to do with your money. You can't just sit around. Like I see some people like mentally can't be away for like a month. You know, to them, it's like being in the Army, they're forced to do it, or it's like, you know, being in jail to them sometimes. (6-months)

Austin acknowledged that the experience could feel coerced and involuntary, but he contrasted his attitude with other participants'. This is not unlike Paolo who gave himself projects to help pass the time in confinement, but for Austin, his focus was on the transformative effect the money he was there to earn could have for his family: "Yeah, it go towards the bills. I'm actually saving for like, it's life insurance for my kids, but in the future, they can take it out for college" (baseline). Like most participants, Austin's motivation to endure studies was in part shaped by his strategy to use studies to provide for his family in the short term by paying bills, but unlike many participants, he also had a longer-term plan of using studies to save for his children's education. Likewise, Roman, a black man who was a long-time study participant, estimating he had enrolled in over 200 studies in twenty years, also contrasted himself with other participants:

Then you got the ones that have done jail time, want to equate this to jail: "Oh, this feels like when I was locked up." So, I look at them, "You had to wear scrubs when you was locked up?" Or I'll say to them like, "You could take a shower anytime you want when you was locked up?" And they look at me like, "You know what I mean." "No, I don't. I really don't." ... That's an institution where you can't leave no matter what you do. This, you can leave. You come in on Monday; you can leave on Friday if you want. You're going to leave with Friday's pay [rather than the full amount], but you can leave, you know what I mean? So you can't equate this to that. (baseline)

For Roman, the fact that he chose to enroll in studies and can leave at will were key reasons why he contrasted the clinic with prison. The other critical aspect was that he believed, even in spite of his long-term participation, that with just a few more studies, he could quit studies and be a small-business owner instead. He explained his goal,

I see the next two years of studies going towards me opening up a business or doing something that will prepare me to stop [enrolling in studies]. I'm considering taking all my study money and putting it into a retirement plan for the next two years [as a way of saving it], just take all the checks and just retirement, retirement, so that's like four to six studies a year, that's 12 studies [total] for two years. (baseline)

In other words, for both of these participants, clinical trials offered a way to save for a future that few other financial opportunities would allow. While Roman also emphasized the voluntary nature of studies as another point of contrast with prison, it was quite striking that he had been serially enrolling in Phase I trials for the past two decades and appeared to be in no better financial situation now than he was in the 1990s. This could indicate that he was trapped in the myth of the transformational potential of clinical trials, harboring the unattainable belief that it would just take another two years to reach his financial goal, keeping him enmeshed in the research enterprise.

For some healthy volunteers, the financial incentives for participation were used to contrast Phase I trials with a prison. While most healthy volunteers, regardless of whether they compare or contrast the clinic to prison, would likely agree that the monetary reward was worth the confined experience, those who argued that it was not like prison tend to focus on the broader value of the compensation for the time spent. The exchange is not just cash payment, but rather it is a promise of a better future, which can be shorter or longer term depending on the participant. In this way, the clinical trial experience is also a temporal total institution: it promises the possibility of a form of reinvention in exchange for consenting to the constraints of study participation.

## Conclusion

Healthy volunteers' mobilization of prison analogies when describing Phase I participation reveals aspects of their personal clinical trial experience but also the larger constraints of their social positions. The clinic was like a prison not only because of the material conditions of the study, but also the economic conditions that compel participation to begin with, making their time feel coerced because they cannot leave without foregoing the better part of their compensation. This might help to explain why those who are unemployed are most likely to compare the clinic to prison. At the same time, participants contrast Phase I trials with prisons because the fixed-term financial exchange has the potential to transform their lives for the better. By comparing or contrasting the clinic with prison, healthy volunteers explicitly draw attention to Phase I trials as a type of total institution.

Goffman's (1961) conceptualization of total institutions has been updated and developed by scholars to account for subtler institutional workings of power (e.g., Davies 1989; Scott 2010; Ritzer and Liska 1997). It is thought that contemporary societies have all but done away with totalizing authoritarian institutions; instead, people often willingly sign-up and take part in their own subjugation (Scott 2010). Phase I trials illustrate the complex nature of contemporary total institutions. We have argued that these research studies function as *temporal* total institutions in that they temporarily subject participants to coercive terms of confinement, maintain dehumanizing environments, and offer the promise of a reinventive experience. While Phase I trials are formally voluntary, healthy volunteers are nonetheless powerless to set the terms of their participation. Additionally, the threat of losing their compensation acts coercively to make healthy volunteers, in an important sense, captive to the clinic once the study begins. They have the right to leave should they so choose, but this agency is constrained by their broader socioeconomic contexts. The narratives of healthy volunteers by and large suggest that rather than experiencing Phase I trials as an empowering reinventive institution as Scott has defined it, healthy volunteers are more likely to view the clinics as repressive in the Goffmanian sense. Unlike the indoctrinated individuals who Scott describes as consumers of the "self-discovery" offered by membership in reinventive institutions, healthy volunteers instead recognize that any transformation that results from their participation stems from the compensation and not the clinical trial experience itself. Thus, when voluntariness is constrained by social and economic inequalities, individuals might determine it is the right choice to submit to highly-controlled and dehumanizing environments. Our conception of temporal total institutions aims to account for this type of voluntary participation in coercive institutions.



Given the economic condition of most healthy volunteers, who tend to be poor, working class and minority, their choices are restricted by their economic insecurity. The racialized social system (Bonilla-Silva 1997) in the U.S. constrains opportunities for non-whites, which places them at the bottom of the economic hierarchy (Bobo 2011; Feagin 2013; Oliver and Shapiro 2006). Inequality has increased markedly in the U.S. in the last several decades (McCall and Percheski 2010), and the case of Phase I trials demonstrates that the consequences of increased inequality can sometimes be hidden within non-traditional institutions of social control. Persistent economic insecurity among non-whites may motivate them to enroll continually in Phase I trials. Participants try to “reinvent” themselves financially in the absence of other economic or employment opportunities. Yet, in spite of their hopes, the money quickly disappears, the participants need more, and they continue to enroll in studies. In this way, being trapped by their own economic insecurity further imprisons them in the institution of Phase I trials even when they are not confined to a clinic. Seen in this light, the consequences of inequality are not only in the quantitative disparities, but in the creative ways in which people try to make ends meet in the face of them (Monahan and Fisher 2015). For instance, inequality brings people into exploitative relationships with financial institutions, such as banks and payday lenders (Gallmeyer and Roberts 2009), much to the dismay of social critics. These organizations might also benefit from being analyzed as temporal total institutions when viewed as playing a key role in exploiting and reproducing existing social inequalities. In Phase I trials, these social inequalities are brought to the fore by the fact that participants in some way look to “transform” and reinvent their lives, not to become better people, as Scott (2010) has argued, but to transform untenable social and economic positions. The example of Phase I trials underscores the importance of analyzing contemporary total institutions by attending to how racial and economic inequalities undermine voluntariness. Until a fundamental transformation of the structures that perpetuate inequality are changed, poor and minority populations may increasingly depend on other means of transformation that ironically may further embed them in cycles of oppression and subjugation.

### Appendix: Demographics at Baseline of Quoted Participants

- Austin: Non-Hispanic black man, 20s, some college (no degree), employed part-time, \$25,000-\$49,999 household income, 3<sup>rd</sup> clinical trial
- Charlie: Non-Hispanic white man, 40s, some college (no degree), employed part-time, \$10,000-\$24,999 household income, 60<sup>th</sup> clinical trial
- Darius: Non-Hispanic black man, 30s, some college (no degree), employed part-time, \$25,000-\$49,999 household income, 10+ clinical trials
- Derek: Non-Hispanic black man, 30s, some college (no degree), not employed, \$25,000-\$49,999 household income, 2<sup>nd</sup> clinical trial
- Elena: Hispanic white woman, immigrant, 40s, less than high school, not employed, less than \$10,000 household income, 3<sup>rd</sup> clinical trial
- Everett: Non-Hispanic black man, 40s, vocational training, not employed, \$50,000-\$74,999 household income, 24<sup>th</sup> clinical trial

- Morgan: Non-Hispanic white man, 50s, vocational training, not employed, \$10,000-\$24,999 household income, 15<sup>th</sup> clinical trial
- Natasha: Non-Hispanic white woman, immigrant, 30s, associate's degree, not employed, \$50,000-\$74,999 household income, 45<sup>th</sup> clinical trial
- Owen: Non-Hispanic black man, 20s, vocational training, employed full-time, \$10,000-\$24,999 household income, 4<sup>th</sup> clinical trial
- Paolo: Hispanic white man, 30s, high school/GED, not employed, \$25,000-\$49,999 household income, 20<sup>th</sup> clinical trial
- Rafael: Hispanic black man, 20s, some college (no degree), not employed, less than \$10,000 household income, 20<sup>th</sup> clinical trial
- Roman: Non-Hispanic black man, 30s, some college (no degree), not employed, \$25,000-\$49,999 household income, 200+ clinical trials
- Sally: Non-Hispanic white woman, 40s, some college (no degree), not employed, \$10,000-\$24,999 household income, 1<sup>st</sup> clinical trial
- Sherrie: Non-Hispanic white woman, 30s, associate's degree, employed full-time, \$25,000-\$49,999 household income, 2<sup>nd</sup> clinical trial
- Travis: Non-Hispanic black man, 40s, some college (no degree), not employed, \$25,000-\$49,999 household income, 50+ clinical trials
- Zach: Non-Hispanic white man, 30s, high school/GED, employed part-time, \$25,000-\$49,999 household income, 6<sup>th</sup> clinical trial

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**Table 1**

Demographics of All Study Participants (N=178) and of Respondents Making Prison Analogies (n=67)

	All Study Participants	N = 178	Prison Analogies	N = 67
	n	%	n	% within subgroup (denominator = 67)
<b>Gender</b>				
Women	47	26.4%	16	23.9%
Men	131	73.6%	51	76.1%
<b>Clinical Trial Experience</b>				
1 study	38	21.3%	9	13.4%
2-4 studies	49	27.5%	19	28.4%
5-10 studies	45	25.3%	19	28.4%
11-200 studies	46	25.8%	20	29.9%
<b>Race/Ethnicity</b>				
Non-Hispanic white	57	32.0%	25	37.3%
Black/African American	72	40.4%	27	40.3%
American Indian	2	1.1%	1	1.5%
Asian	6	3.4%	0	0
Hawaiian/Pacific Islander	2	1.1%	1	1.5%
More than one race	13	7.3%	4	6.0%
Hispanic <sup>1</sup>	38	21.3%	14	20.9%
<b>Age</b>				
18-21	6	3.4%	2	3.0%
22-29	34	19.1%	13	19.4%
30-39	58	32.6%	29	43.3%
40-49	54	30.3%	16	23.9%
50+	26	14.6%	7	10.4%
<b>Household Income<sup>2</sup></b>				
Less than \$10,000	30	16.9%	9	13.4%
\$10,000 to \$24,999	52	29.2%	19	28.4%
\$25,000 to \$49,999	71	39.9%	30	44.8%
\$50,000 to \$74,999	13	7.3%	4	6.0%
\$75,000 to \$99,999	7	3.9%	3	4.5%
\$100,000 or more	4	2.2%	2	3.0%
<b>Educational Attainment</b>				
Less than high school	12	6.7%	2	3.0%
High school or GED	37	20.8%	15	22.4%
Some college	52	29.2%	24	35.8%
Trade/technical/vocational training	19	10.7%	8	11.9%
Associate's degree	21	11.8%	7	10.4%

	All Study Participants	N = 178	Prison Analogies	N = 67
	n	%	n	% within subgroup (denominator = 67)
Bachelor's degree	32	18.0%	10	14.9%
Graduate degree	5	2.8%	1	1.5%
<b>Employment Status<sup>3</sup></b>				
Full-time/Business owner (self-employed)	45	25.3%	14	20.9%
Part-time/Independent or Irregular Contractor	60	33.7%	19	28.4%
Unemployed/Retired	73	41.0%	34	50.8%

<sup>1</sup>The category Hispanic includes all racial groups, of which we have those that identify as white, black, more than one race, and Native American Pacific Islander in our sample.

<sup>2</sup>Data for household income was not reported by one participant.

<sup>3</sup>These data are based on consolidated definitions of each employment category that we used to standardize self-reported data from participants.

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