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Article

Moving out of the Human Vivarium: Live-in Laboratories and the Right to Withdraw

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Abstract: Homes are increasingly being built as sensor-laden living environments to test the performance of novel technologies in interaction with people. When people's homes are turned into the site of experiments, the inhabitants become research subjects. This paper employs findings from biomedical research ethics to evaluate live-in laboratories and argues that when live-in laboratories function as a participant's main residence, they constrain an individual's so-called 'right to withdraw'. Withdrawing from the live-in laboratory as a participant's main residence means losing one's home, which creates negative financial and psychological consequences for participants. I will argue that such costs conflict with a participant's right to withdraw on two counts. First, the exit costs from the live-in laboratory constitute a penalty, and second, the costs of withdrawing from the live-in laboratory function as a constraint on a participant's liberty. The paper concludes that (i) the right to withdraw is a necessary condition for the ethical permissibility of modern live-in laboratory experiments and concludes (ii) the practice of making an experimental home a participant's main residence is ethically problematic.

Keywords: experimental homes, live-in laboratory, research ethics, human experimentation, right to withdraw, exit costs, human subject research

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1. Introduction

What if withdrawing from an experiment means losing your home (Taylor 2020)? In the last two decades, living environments have been constructed for the explicit purpose of performance and hypothesis testing, while hosting participants as residents, such as the MIT PlaceLab or Georgia Tech's Aware Home. These experimental living environments, often called live-in laboratories, aim to bridge the research benefits of a controlled laboratory setting with extensive fieldwork (Intille et al. 2005).

But, when homes become laboratories, their inhabitants become research participants. Live-in laboratories exemplify an intimate relationship with their research participants that few research

methodologies possess. Residents are subjected to a perpetual state of exposure to a variety of experimental interventions and forms of data capture depending on the technologies tested. Live-in laboratories thus have strong research ethical implications. Regardless, while individual studies in live-in laboratories might be subject to ethical review, the ethics of live-in laboratories as a research platform has received limited academic scrutiny.

Research ethics is often applied or upheld alongside institutional boundaries, meaning researchers or institutions external or in collaboration with a university usually do not fall under the scope of ethical review not bound to such guidelines. Live-in laboratories often operate as zones of innovation on the border of collaborations between knowledge institutes and public and private parties. Here, researchers can research, test and develop, new solutions or technologies in a near-to-real-use setting. In some cases, local laws are suspended to create an environment (often called a 'sandbox') in which innovation is unhampered by regulation (Taylor 2020; Ranchordas 2021). Consequently, research ethics obligations are obscured. Scientists conducting research with or on live-in laboratory residents might be required to meet human research ethics board requirements, however, such guidelines do not apply to non-academic researchers.

Urban environments both public and private are increasingly framed as experimental locations where solutions for societal challenges can be found through research and technological innovation (Maas et al 2017; Baccarne et al. 2014). While experimental practices outside the laboratory are bound by positive law, what is missing, as Taylor notes, is an "interrogation of urban experimentation that takes seriously the issue of research on human subjects, and asks what norms, rules and boundaries are appropriate" (Taylor 2020, 1903). This paper provides such an interrogation.

Taylor has suggested framing urban technological experimentation through a research ethics lens (Taylor 2020). One of the practical features of research ethics is that it awards research participants, what Taylor calls, "avenues of resistance" against asymmetrical power relations between researcher and participants (Taylor 2020). Such 'avenues of resistance', for example, preserve participants' freedom from constraints that urge a certain action and provide participants with a certain level of control over potential research risks that they are subject to, but do not necessarily control or benefit from. This lens applies to live-in laboratories since they are an experimental apparatus the usage of which functions as a research methodology to conduct hypothesis and performance testing on and with human subjects. However, it is exactly such resistance that the live-in laboratory renders ineffective.

In those cases where live-in laboratories function as a research participant's main residence, withdrawing causes negative consequences for participants, which constrain a participant's liberty to effectively exercise their right to withdraw from research. This right is an ever-present ethical principle in contemporary moral codes regulating research on human participants and functions as an important mechanism which helps realize the bio-ethical principle of autonomy in the conduct of an experiment.

The paper proceeds as follows. First, I define live-in laboratories and explain how withdrawing poses negative consequences for participants. Next, I describe the residents of live-in laboratories as a subject pool that has received limited research ethical attention. I then argue that if an experiment is ethically permissible, a participant is free to exercise their right to withdraw freely without penalty. Then, I show that the cost of withdrawing from a live-in laboratory qualifies as a penalty and that the (unintended) threat of said costs acts as an unjust controlling influence on a participant's liberty to exercise their right to withdraw. Finally, I conclude that the live-in laboratory is an ethically problematic experimental setup and suggest that investigators should aim to nullify the associated costs of withdrawal, or only conduct research on temporary residents who do not face exit costs.

2. Experimentation and the Live-in Laboratory

Live-in laboratories are experimental homes that are used to either study how persons interact with a certain technology, study persons within an instrumented domestic environment or test the performance of a technology in a real living environment inhabited by humans. Live-in laboratories vary in scope, scale and focus. What binds them is that they are real living environments created for hypothesis and performance testing. They are often real homes, with residents, constructed for research purposes. [1]

This paper focuses on two types of domestic live-in laboratories, henceforth labelled as 'Visited Places' or 'Lived-in Places' (Alavi et al. 2020). The main difference between these two types of live-in laboratories is the duration of occupancy. Visited Places are live-in laboratories that host participants for a few hours or days per week and thus are temporary places of living. (Alavi et al. 2020). In contrast, Lived-in Places host

1 There are also examples of offices being designed and built as live-in laboratories, such as the Smart Living Lab in Switzerland (Alavi et al., 2020), which feature experimental and digital technologies that put the space in a constant experimental state.

participants, or residents, for several years and function as a participant's main residence (Alavi et al. 2020).

Let's turn to two examples to clarify the difference. In 2004, MIT constructed the PlaceLab, a live-in laboratory to study domestic ubiquitous technologies (Intille et al. 2005). The PlaceLab is a 1000 sq. ft. apartment embedded with a myriad of sensors including light and infrared cameras, environmental sensors, microphones, state sensors on every object that participants can touch and use and motion sensors. As participants live in PlaceLab for a few weeks at most, this is a Visited Place.

Contrast this with the 'DreamHus' (Frisian for 'dream house') which are part of the Delft University Technology campus (Dreamhus 2021). Standing on the site of 'The Green Village', a real-world testbed for sustainable technologies, the 'DreamHus' are homes built in the image of three 1970s Dutch row houses to test potential innovative solutions to make more sustainable housing. The aim is to scale up efficient solutions to the general (Dutch) housing stock. Current experiments done by an assembly of researchers, students and innovators within the Dreamhus include "solutions in the field of energy, healthy indoor climate, water, heating, insulation, ICT, IoT and Smart homes" (Dreamhus 2021). These three houses are inhabited for two years maximum, with additional studios for students who can stay for up to five years. These live-in laboratories are Lived-in Places since they function as an occupant's main residence.

This paper is especially concerned with live-in laboratories being used as Lived-in Places (LIP from now on). It is unclear exactly how widespread this phenomenon is. However, a recent study looking at the living lab literature between 1999 and 2018 found 19 instances mentioned in the literature sampled (Alavi et al. 2020). Furthermore, there are plans for an entire live-in lab neighborhood called Brandevoort 2, which aims to construct a complete, digitally connected neighborhood in which residents can be continuous research participants and sell their data for rent reductions (for a more thorough discussion of the Brandevoort 2 project, see (Taylor 2020)). Regardless, such live-in laboratories have received barely any ethical scrutiny to date (Taylor 2020). With such practices happening right now - and more in the pipeline- an exploration of the ethics of live-in laboratories is necessary.

LIPs are a research methodology using the live-in laboratory as experimental apparatus and its inhabitants as research subjects. By virtue of being research participants, inhabitants of the LIP should be awarded the right to withdraw without penalty which is an ever-present norm in contemporary scientific moral codes regulating research on human participants. The right protects the participant's ability to withdraw their consent to participate in a research experiment or trial at any time and by effect stop their participation in said experiment or trial without

retribution, reprisal, penalty or loss of benefits (Schaefer and Wertheimer 2010; Edwards 2005; Holm 2011). However, when applying a research ethics perspective to the LIP and extending the right to withdraw to its inhabitants, this paper observes a friction: the costs of withdrawing from a LIP seem to conflict with a participant's right to withdraw from research without penalty (abbreviated as RTW onwards).

3. The Consequences of Withdrawing

Consider the following. A team of researchers have developed a technology (let's call it "T") and would like to gather data on people's interaction with T in a domestic setting. Participant Petra gives informed consent to have T tested and monitored in their home. The research team comes to Petra's home, installs T and takes their leave. During the experiment, Petra, for whatever reason, changes her mind. No longer wishing to partake as a participant in the experiment, Petra informs the researchers and withdraws their informed consent to participate. The research team removes T, leaving Petra and her house as before the experiment. In this scenario, when a participant withdraws from an experiment in a home that temporarily had become an experimental site, the home returns to its state before it was instrumented. Withdrawing from the experiment came at no cost.

Let's compare this to how withdrawing from a LIP would look. Let's take the same team of researchers that have developed technology T who want to gather data on people's interaction with T in a domestic setting. Instead of introducing T within an existing domestic setting of Petra, they decide to construct their own domestic setting – a live-in lab which acts as a home. Again they invite Petra, who gives their informed consent to participate in the experiment, to live in the live-in lab and have their interactions with T monitored. Later, Petra changes their mind about their research participation and informs the researchers that they will be withdrawing their consent to participate in the experiment. Now what happens? As we saw, instead of introducing T to the home, Petra is introduced to the home. Since Petra is the addition to the LIP and not vice versa, it follows that we remove Petra from the LIP.

This is an important difference. While the removal of T from a traditional research setting comes at no cost for Petra, removing Petra from the live-in laboratory comes at a significant cost for her. This consequence is the same if Petra either withdraws themselves from the home or if investigators remove Petra from the home: they are removed from their home and daily life and have to move.

This leaves a participant in an undesirable situation where their housing is contingent on their research participation. If there is no 'baseline

home' to return to, which is the case since the LIP is a participant's main residence, then these participants need to find a new house. Moving house, also known as residential mobility, has several costly implications for a participant, which I will now outline.

First, moving house inflicts economic costs upon participants that wish to withdraw. While financial costs naturally vary based on location, moving is never free. Deposit, mortgage costs, broker fees, estate agent fees, insurance, legal fees, postal redirection, removal and moving companies are but a few examples of the types of financial costs that moving can inflict. As an indication, according to the UK's non-profit Consumers' Association, the average cost of moving house in 2020 was around £7000,- (Maunder 2020). Another point to make is that live-in laboratories might offer residencies below market rent, increasing rent costs for those that (have) to move back to the non-instrumented housing stock.

Secondly, residential mobility has an impact on a person's mental health. Research suggests that there is a link between residential mobility and poorer mental health (Morris et al. 2017). This link seems strongest for adolescents and children. Morris and colleagues outline several pathways through which this effect operates, including weakened social ties, disturbance of social networks, social stress, household disruption and social isolation (Morris et al. 2017).

Additionally, these costs do not happen in a vacuum. The above-mentioned costs are aggravated by their socio-economic context, which, while not a cost in itself, impacts the capacity of a participant to successfully move house. For example, there needs to be available housing to begin with. This greatly depends on local housing situations. Available housing also needs to be affordable to the participant that withdraws from the LIP. Hence, research participants from lower socio-economic classes would have a harder time finding replacement housing, considering factors such as long waiting lists for government-sponsored social housing, a disconnect between increasing rent prices in urban areas and increased wages and minimum income requirements for rental homes. This is a problem since a live-in laboratory would likely attract "experimental subjects who are already on the receiving end of power asymmetries" (Taylor 2020, 1908). Those who will be willing to live in the LIP or feel drawn to its potential lower market rent will be from financially more vulnerable demographics: students, renters, those that qualify for social housing, etc.

Furthermore, moving house is never immediate. This raises questions about the participant's immediate housing status. If there is no immediate alternative, a research participation termination amounts to putting a former participant on the street. If participants are allowed to continue

living in the LIP after research participation has ended for a certain period, questions arise concerning the experimental technology present in the LIP while the resident is no longer a research participant. Will these remain operational, but will the collected data be stopped or destroyed? Will these technologies be removed or turned off? When the LIP is part of an experimental neighborhood of live-in laboratories, can we credibly say the person has withdrawn from the experiment if all their neighbours, the neighborhood or the immediate area surrounding their home is still the subject of research? Such unresolved questions might leave an ex-participant in a state of undesirable uncertainty.

An additional problem can emerge when it's not a single individual who inhabits a live-in laboratory, but instead a group or family [2]. Cohabitation is a common living arrangement. Unless clear regulations were in place to prevent it, it is highly plausible that families or other forms of cohabitation might take residence in a live-in laboratory if it is suited to host more than one resident. In fact, couples do live in the Dreamhûses, the live-in laboratories part of Delft University of Technology's Green Village (2023). This presents an interesting problem for live-in laboratories in particular and any form of research that deals with collective forms of subject participation: what if a member of the cohabiting unit wants to withdraw from the experiment and (the) other(s) do not?

I will distinguish three distinct scenarios that might follow such a predicament. First, if the subject/resident in question decides to withdraw and move out, they face the same constraints as laid out in this chapter so far. Secondly, it might be possible that the resident who wishes to withdraw, does not wish to move out or, at least, is not able to move out right away. This might be due to the nature of the relationship of the residents. For example, a couple might reasonably want to keep living together and parents cannot abandon their children. Alternatively, it might be due to the above-mentioned constraints, such as market forces and the ability of the resident to afford to move. Regardless, in such a scenario we essentially are presented again with the problem outlined in the previous section: where a participant cannot move out immediately and is potentially, by proxy, still involved in an experiment because their neighbours are. In this case, this would be their cohabitants and the challenge of successful withdrawal seems even more pronounced. Thirdly, it might be the case that due to one person wishing to withdraw, everyone else either has - or feels obliged - to withdraw too. These group dynamics pose additional controlling influences on a resident's decision to withdraw. Co-habiting a live-in laboratory with a partner, family or friends could very well influence a participant's decision to withdraw, since if they would choose to do so, either they would have to leave their co-habitation unit or

[2] Thanks to an anonymous reviewer for suggesting this issue.

the whole unit would leave the experiment. I expand on controlling influences in section 6.

Finally, it is important to note that live-in laboratories might have specific conditions under which persons can inhabit them. These conditions can influence the degree to which withdrawing causes certain consequences. The exact site-specific conditions of a given live-in laboratory are outside the scope of this paper. However, for the sake of providing an example to this point, I will briefly outline several conditions concerning the aforementioned live-in laboratories, based on the earlier typology (Visited Places vs Lived-in Places).

First, considering the two LIPs which were mentioned earlier, Green Village and KTH Live-in Lab, residents receive a rental contract for housing that is equal to or below market rent[3][4]. Contracts are offered for a set period, ranging from one year to a maximum of a few years. In return, through living their daily life and interacting with a variety of experimental systems, certain technologies can be tested and developed. Additionally, they are encouraged to engage with other projects that require more active participation.[5] Turning to the VPs, MIT PlaceLab residents were reportedly volunteers (Roberts 2011). While not mentioned, I take this to mean they did not pay rent and potentially received (limited) benefits This would be plausible given that residents only stay in the Placelab for up to a week or two.

A recurring selection criterion for residents seems their interest in the experimental work conducted at the live-in laboratory (KTH 2020). Participants/residents are partially selected on their motivation and personal connection to overall research themes. It is plausible this will translate into a more interested, engaged and complacent resident body; increasing the likelihood of a smooth relationship with residents during their stay. Having an altruistic sense one has the opportunity to contribute to problems on research themes that they value – say sustainability – runs the possibility of not only keeping participants engaged but also morally bound to the project.

[3] In the case of the Green Village, personal correspondence with staff informed me that their housing rent is below market value. The housing stock consists of studios (generally for students) and larger family homes, housed by individuals or couples.

[4] An application post for residency in the KTH Live-in Lab notes how the rent will mirror other apartments the university offers (KTH 2020). The price quoted is 5000-6000 SEK/month. The housing stock consists of shared (student) housing.

4. Live-in laboratory residents as an unrecognized human subject population

Residents of live-in laboratories are a human subject pool essential to the live-in laboratory as a research methodology that aims to emulate a near-to-real-use setting. However, LIPs are not being classified as human experimentation due to two main reasons. First, the scope of research ethics regulation is strongly tied to those institutions that apply for federal or governmental funding, leaving the live-in laboratories of private parties outside this scope. Additionally, when live-in laboratories are part of a collaboration between knowledge institutions, public organizations and private parties (so-called triple helix collaborations), research ethical obligations might get obfuscated. Secondly, while individual studies conducted in LIPs might meet the criteria for counting as research (with human subjects), the LIP and the act of living in a LIP itself are not research. Instead, they constitute the creation of a continuously available and exposed subject pool. Residents are exposed to a variety of research practices that may or may not qualify as human subject research, yet the LIP itself remains outside of regulatory scope. I will expand on these points below.

Research ethics regulation is commonly applied alongside the institutional boundaries of universities or similar research institutions. To qualify for or attract governmental funding, universities etc. have to comply with the funding organizations' ethical review regulations (Moffat 2010). For example, the US Federal Policy for the Protection of Human Subjects, also known as the Common Rule, only applies to behavioral and biomedical research that receives federal US funding and is conducted at academic or other intuitions "for which a federal department or agency has specific responsibility for regulating as a research activity 945 CFR 46.102(e)). Similarly, researchers or institutions applying for funding at the European Union (EU) have to comply with ethical guidelines set out by the EU (European Union, 2013).

As a result, companies – or any institution – that do not seek such funding or operate outside the institutional boundary of those that do, are therefore not legally bound to certain ethical regulations (Benbunan-Fich 2017). There are many forms of experimentation, for example, corporate A/B testing (Benbunan-Fich 2017), traffic experimentation (Richter et al. 2001; Svensson and Hansson 2007) the testing of self-driving cars on public roads (Stilgoe 2020), experiments with predictive policing (Amnesty 2020) that might benefit from ethical review, yet are not the subject of human research ethics regulation, since the investigators are not tied to regulatory commitments to the same degree as researchers working at a university. A famous example of this was the Facebook Emotional Contagion study, in which researchers at Facebook, in collaboration with Cornell University, studied how emotions spread among users of the platform. The Cornell

University researchers had sought IRB approval for this study but since data collection was technically done independently from Cornell by Facebook researchers before their involvement, the Cornell review board judged that no review was necessary (Flick 2016).

When conducted by parties tied to federal funding, what matters in terms of regulatory scope is whether a certain activity meets the definition of research or human subjects research. If a certain activity falls outside the definitions, research ethics regulation currently does not apply.

Research is commonly defined as an activity characterized as a systematic investigation with the intention to develop generalizable knowledge (US HHS 45.CFR.46). Here, I follow the Harvard Committee on the Use of Human Subjects which defines investigation as a "methodical procedure and plan, is theoretically grounded, and specifies a focused and well-defined research problem or question, is informed by the empirical findings of others, is analytically robust, and provides a detailed and complete description of data collection methods" (Harvard CUHS). Drawing again from the Harvard CUHS, generalizable knowledge can be defined as information that "is expected to expand the knowledge base of a scientific discipline or other scholarly field of study and yield … results that are applicable to a larger population beyond the site of data collection or the specific subjects studied [or] results that are intended to be used to develop, test, or support theories, principles, and statements of relationships, or to inform policy beyond the study." (Harvard CUHS)

Human subjects, as defined by the Common Rule (US HHS 45.CFR.46), are any living individuals about whom an investigator conducting research:

(i) "Obtains information or bio-specimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or bio-specimens; or

(ii) Obtains, uses, studies, analyzes, or generates identifiable private information or identifiable bio-specimens."

Different studies conducted in or with live-in laboratories can both fall within and outside the scope of these definitions. For example, university researchers conducting a study on how a certain nudging technology influences residents into a more sustainable behavioral pattern would fit all the definitions above. Applying a new type of heat isolation in the walls in the live-in laboratory to study its performance might be classified as research but not human-subject research. An example that fits none of the two definitions would be interviews with residents conducted by a local newspaper on how they enjoy their stay.

A problem then emerges in which certain types of research and the live-in laboratory itself as a platform for experimentation stay out of shot

of regulatory obligations. Letting persons live in homes that are under contentious experimentation is not research in itself. It is the creation and demarcation of an ever-ready and available subject population that can be exposed to a series of overlapping experiments that involves and impacts them to various degrees, which may or may not fall within the defined scope of human subject research. However, we cannot treat their involvement in research that falls within or outside this scope as separate. Take the aforementioned example of the researchers testing new forms of insulation in the walls of the LIP. Even when subjects are not directly involved in data collection, when this intervention turns out to not work or be toxic, it will be residents who are directly affected.

In recent years, there has been increased scholarly attention on the question of what justifies the boundaries of research ethics regulation (Hansson 2011; Wilson and Hunter 2010). For example, the rise of company-sponsored online experimentation has received scholarly attention to the fact that these practices are not covered by research ethics regulation, yet pose similar ethical concerns for subjects as with scientific research (Benbunan-Fich 2017). Similarly, the residents of LIPs are a vulnerable research population, which due to the intertwinement of their residency with participation and the costs of withdrawing, might not be as well-suited to protect their interests as other research participants might be. If we allow people to participate in live-in laboratories, this participation should be informed by the constraints and influences placed upon residents and the importance of the right to withdraw.

5. Ethical Experimentation and the Right to Withdraw

In this section, I deploy two strategies in order to that if an experiment is ethically permissible, a participant is free to exercise their right to withdraw without penalty. First, is to make an appeal to codified research norms as the source of an experiment's moral permissibility and hold that this is determined by its capacity to comply with research ethics guidelines and, subsequently, be deemed acceptable by ethics commissions or institutional review boards (IRB's). I call this the institutional defense. Afterwards, I will provide a moral defense grounded within bioethical principlism.

5.1. *An Institutional Defense of The Right to Withdraw*

The institutional defense holds that an experiment's ethical permissibility is grounded in the judgement or authority of a research ethics committee or institutional review board (IRB). Such a view is for example articulated by Paul McNeill in his book 'The Ethics and Politics of Human Experimentation':

"The principle method for ensuring that human experimentation is ethical is to require researchers to have their proposals for experimentation on human subjects approved by a research ethics committee" (McNeill 1993, 1).

Such approval is generally contingent on whether an experiment's design complies with international documents that set global research practice standards for the permissibility of an experiment's design, process or effects on human subjects.

The justification for extending the RTW to research participants is hence grounded on them being present in those documents that set the global convention of ethical research which influence IRB's approval. The RTW is such a right. Edwards has stated that a reference to the RTW "is now included almost mechanically by researchers and research ethics committees alike" (Edwards 2005, 114).

Let's turn to influential contemporary sources that explicitly mention the RTW. For example, The Declaration of Helsinki (1964, latest revision in 2013) from the World Medical Association states in its 26th principle that:

"The potential subject must be informed of the right to refuse to participate in the study or to withdraw consent to participate at any time without reprisal" (2013).

A similar definition appears in the 'International Ethical Guidelines for Health-related Research Involving Humans' (1993, latest revision in 2016) by the Council for International Organizations of Medical Sciences (CIOMS), which was founded by the WHO and UNESCO: "participants have a right to withdraw at any point in the study without retribution" (2016, 33) and "the individual is free to refuse to participate and will be free to withdraw from the research at any time without penalty or loss of benefits to which he or she would otherwise be entitled (Guideline 9)" (2016, 103).

Similarly, The Belmont Report (1979), which was drafted by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the aftermath of the Tuskegee Experiment Scandal, mentions that a prospective participant should be presented with "a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research" (National, 1979, 6). While the Belmont Report does not specifically mention the fact that a participant has a right to withdraw without reprisal, it does so de facto by denouncing "unjustifiable pressures" that "urge a course of action for a subject" (idem, 7) examples of which include "threatening to withdraw health services to which an individual would otherwise be entitled" (idem, 8).

However, holding institutional research norms as the grounds on which we should judge an experiment's ethical permissibility, might not

be convincing. This defense, merely, shows that LIPs are not in accordance with current institutional guidelines about ethical experiments. While an interesting conclusion, this argument might be too conventional to provide a satisfactory ground on which to judge the permissibility of an experiment. Indeed, history is filled with examples of experiments or trials on human subjects that did receive ethical approval by IRBs but did later turn out to be highly problematic. Often a major scandal must occur before any reform in ethics codes is seriously undertaken and what might be impermissible now, would have been permissible several decades ago (McNeill 1993). To satisfy this concern, in the next section, I will aim to provide a moral defense of the claim that the RTW is a necessary condition for an ethical experiment grounded within bio-ethical principlism (Beauchamp 2016).

5.2.A Moral Defense of The Right to Withdraw

Principlism in bioethics arose in the 1970s through two major works - the Belmont Report and the 'Principles of Biomedical Ethics' by Beauchamp and Childress (Beauchamp 2016). It aimed to ground the conduct of biomedical research on human subjects not on professional conduct, but on moral principles. Principlism offers a practical, pluralistic tool for bio-ethical decision making, sidestepping high moral theory and providing an intuitive framework of, in the words of Beauchamp, "general guidelines that condensed morality to its central elements" (Beauchamp 1995, 181). These principles are (1) respect for autonomy, (2) beneficence, (3) non-maleficence and (4) justice. Non-maleficence was created as a separate principle by Beauchamp and Childress and was in the Belmont Report understood to be included under the principle of beneficence.

The aforementioned four principles do not constitute the full set of common morality, but according to Beauchamp, a selection is necessary for the construction of a normative framework for biomedical ethics (Beauchamp 1995). The principles are understood to be non-absolute, with no principle taking precedence of another, and prima facie, so binding unless they conflict with other moral principles, which allows them to be overwritten by other moral considerations (Beauchamp 1995). While developed in the context of biomedical ethics, the principles have since been applied to structure ethical decision-making in human subject experimentation in general.

Beauchamp holds that certain principles are necessary for promoting human flourishing. Beauchamp claims that there is a "tendency for the quality of people's lives to worsen", which certain principles help to counteract (Beauchamp 2016, 9) What justifies the principles is simply that they are those norms that are effective, or as Beauchamp puts it:

"Best suited to achieve the objective of morality, which is the promotion of human flourishing by counteracting human circumstances in

interactions with others that cause the quality of people's lives to worsen" (Beauchamp 2016, 9).

I argue that the right to withdraw can be understood as a prerequisite to a participant's liberty, understood to be a necessary condition to the principle of autonomy. Beauchamp holds two concepts to be necessary conditions for a person's autonomy; liberty and agency (Beauchamp 2016). The focus of my argument is on liberty, which Beauchamp defines in the negative sense, as "the absence of controlling influences" (Beauchamp 2016, 5). I hold that the function of the RTW is to realize this notion of liberty by providing mechanisms to participants that prevent said controlling influences on their liberty. In other words, the function of the RTW is to prevent investigators from placing constraints on withdrawing from research to safeguard a participant's liberty.

However, here we run into two problems. First, we aim to defend not only that an experiment is ethical if participants have the right to withdraw from research, but that they have the right to withdraw from research without penalty or loss of benefits. The question stands whether penalizing a research participant can be defined as constraining a participant's liberty. I believe that penalizing does constrain a participant's liberty to withdraw from research. Here I understand constraints on a person's liberty in a broad sense, including next to intended obstacles, restrictions or interferences, also unintended obstacles (Carter 2003). Penalties pose a certain obstacle or interference to people. Exiting costs of a live-in laboratory might not be an intended policy, yet even if unintended, they can constrain a participant's freedom, since penalties are a controlling influence. The threat of penalties might deter people from certain actions and urge a certain course of action. I argue in the next chapter that we can understand the costs of withdrawing in a LIP as (potentially unintended) penalties.

A second challenge that we encounter is that all principles in principlism, including respect for autonomy, have prima facie standing (Beauchamp and Childress 2001). While we can imagine many scenario's in which other principles outweigh a participant's autonomy, in the case of the LIP, there are no good overwriting moral reasons that justify the constraint of a participant's liberty that urge them to stay in the LIP experiment. Imposing such costs does not benefit the participant. It harms them. Neither is the research of such immediate societal impact or danger that keeping participants in the experiment could be justified based on protecting others from harm. Several authors have argued on this basis that in certain experiments, such as infectious disease studies (Fernandez Lynch 2020) or xenotransplantation (Spillman and Sade 2007) we should not award participants the RTW. However, the LIP conducts no research that poses a danger to society when its participants withdraw. Finally, placing penalties on withdrawal in this form of experimentation is an unjust

distribution of the benefits and costs of research participation. While beneficial to the researcher and innovators, residents do not necessarily directly benefit from successful innovations that are tested in LIPs as might be the case with experimental medical trials, in which a patient's health is at stake. Hence, there are no overwriting reasons to curb a LIP participant's right to withdraw.

6. Do the Costs of Withdrawing Qualify as a Penalty or Loss of Benefits?

Earlier, we have shown that withdrawing from a LIP can cause participants financial and mental strains because they need to find a new home. This process can be strained due to external factors such as the availability of housing, the capacity of participants to obtain housing and the uncertain limbo state between withdrawing from the experiment and moving into a new home. In this section, I argue that such consequences count as penalties or losses of benefits that a person is otherwise entitled to.

A common definition frames a penalty as a punishment in reaction to an individual who has violated a rule. In other words, deliberate action in reaction to a violation with the intent to punish. Legal philosopher Joel Feinberg argued in his 1965 paper 'The Expressive Function of Punishment' that while penalties and punishments are both "authoritative deprivations for failures", their difference lies in their level of expressiveness, with punishment having a "symbolic significance largely missing from other kinds of penalties" (Feinberg 1965, 400).

However, this intentional notion of a penalty only allows us to qualify the negative consequences that are intentionally given in reaction to said participant withdrawing their research participation consent as penalties. While I do not want to exclude this possibility, I aim to conceptualize penalties without relying on intention, since the design and operation of the live-in lab generate a certain environment from which certain negative consequences arise upon withdrawal rather than from the intentions of the investigators.

How about a loss of benefits that a participant is otherwise entitled to? Schaefer and Wertheimer maintain that participants are entitled to those things that were promised to them on either the completion or partial completion of research (Schaefer and Wertheimer, 2010). Benefits are akin to compensation promised. So not providing a benefit to a participant that was part of the research participation, does not necessarily mean that a participant is losing out on something that they would be entitled to, as long as a participant receives what they were promised for the work that they did. A participant would be penalized when receiving less than promised. This seems in line with the CIOMS guidelines, which recommends that those that withdraw from research themselves should be

compensated proportioned to the part they have completed. In this case, a participant is not entitled to the full amount (CIOMS 2016).

However, if live-in lab participants were promised a new home upon withdrawal and they would not receive it, this would then constitute a loss of benefits that a participant is otherwise entitled to. Again, this seems a possible scenario, however, I do not wish to build my defense of this contingency. So it seems that this notion is also not helpful to frame the possible costs as penalties.

A potential strategy is to consider the protective intent with which the RTW was introduced into research ethics guidelines. The original inclusion of 'without reprisal' is linked by Melhalm and colleagues to the needs of an important research demographic of (bio)medical research: patients (2014). They state:

"Because many participants are recruited by virtue of being patients, in order for their choice to be meaningfully voluntary there must be assurance that abstaining or withdrawing will not compromise their current and future clinical care" (Melhalm et. al. 2014, 3).

The 'without penalty' quality of the RTW – and the 'voluntariness' it was aimed to protect - was therefore originally included to compensate for a patient's natural vulnerability, preventing the threat of losing out on relevant care upon withdrawal would urge a certain course of action of patients. To clarify, the RTW does not ensure that participants can participate and have a right to withdraw unscathed. After all, often research involves certain justifiable risks. However, what the RTW does aim to protect is that withdrawing from participation in itself does not leave a participant worse off than they were before participating.

If we conceptualize penalties in the case of the RTW as reductions of a pre-experiment baseline due to withdrawal, then we can categorize the negative consequences of withdrawing from a live-in lab as penalties. Since withdrawing itself, not the risks that a participant endures during the experiment leaves a participant arguably worse off than before they participated. This definition circumvents the intentional problem and the promise problem, by not making the definition of penalty contingent on an intentional character and not focusing on defining a penalty in relation to what a participant was promised for (part of) their research participation. Instead, it focuses on a comparison of a participant's baseline previous to LIP participation and how withdrawing itself penalizes a participant compared to this pre-experiment baseline.

7. Do the Costs of Withdrawing Act as Unjust Controlling Influences?

Earlier, I argued that the RTW is a necessary condition for a participant's liberty, understood in Beauchamp's negative sense as "the

absence of controlling influences" (Beauchamp 1995, 5). This section argues that the potential costs of withdrawing in a LIP could be categorized as a constraint on a participant's liberty since they pose *controlling influences*. This is problematic since this paper holds that, within the context of human experimentation, liberty is a necessary condition for the principle of autonomy, one of the four moral principles structuring bioethical thought on human experimentation. If a participant in an experiment lacks that liberty for no apparent justifiable overwriting reason, such an experiment should be considered morally suspect.

There exists a strong link between the activity of research participation and the notion of voluntariness. Not only is participation in research understood to be voluntary (Levine 1996), but also a participant's agreement to participate in research – their informed consent – rests on voluntariness. The RTW should be understood as an essential part of informed consent (Nelson and Merz 2002). Hence, just as a participant's informed consent is only understood to be meaningful if a participant gave their informant consent voluntarily - meaning free from unjust pressures, undue influences or coercion – so is their right to withdraw. As mentioned earlier, the original inclusion of the 'without penalty' clause was motivated to ensure that a potential participant's choice to participate and stop participating would be meaningfully voluntary given their vulnerable status. In order words, for informed consent and the RTW to be meaningful, one needs to be able to exercise it voluntarily.

This paper outlined several financial, psychological and social costs which are amplified by certain context-dependent factors which affect a participant withdrawing from the LIP. The prospect of having to endure the aforementioned cost urge a certain course of action for a participant, namely they influence one's decision-making concerning whether they would withdraw from the experiment.

This scenario seems akin to other situations in which a person is awarded a certain right, but external factors inhibit the right from being freely exercised if a person does not possess a reasonable capacity to overcome those factors. If a person has a right to vote, but risks losing their job and hence livelihood, when they have to stand in line all day to exercise that right, one might be pressured into a certain course of action, namely to not go vote. Similarly, research showed that when US citizens had a federal right to abortion and US states were limited in their capacity to prohibit them, abortions can be discouraged nonetheless through, what Johnson and Bond call, "a variety of coercive and non-coercive policies that might operate to alter the utilities associated with having or providing abortions" (1980, 106).

Imagine a participant that wants to terminate their research participation. They realize that this would mean they have to move out of

their house and that this will be financially and emotionally costly for them. Perhaps, they do not have the funds to find alternative housing. Such considerations about future potential costs can be reasonably assumed to influence some LIP participants into either postponing their withdrawal or forgetting about the idea altogether. Whether participants necessarily are aware of those costs or consider them to be of no influence is irrelevant to their existence being a possible influence on those participants that do consider and are influenced by them. So the cost functions as a pressure which urges a certain course of action, which is to not withdraw. As argued earlier, we have no reason to assume that the costs of withdrawing from the LIP qualify as potential justified pressures. In other words, a participant of the LIP is unable to freely exercise their right to withdraw.

8. Conclusion

In this paper, I have identified the negative consequences of withdrawing from a laboratory that is also a participant's home and argued that these consequences are morally problematic when held against an appropriate normative research framework. Specifically, participants are unable to withdraw from research without the (threat of) losing their homes. This strains a research participant's ability to exercise the right to withdraw, which they are awarded based on the virtue of them being research participants. I have grounded the ethical justification of the RTW in both institutional convention and biomedical principlism as a mechanism for realizing a participant's liberty, understood as a necessary condition for the value of autonomy. I have shown that the negative consequences of withdrawing from a LIP can both be categorized as a penalty and a controlling influence, meaning LIP participants are not able to exercise their RTW freely and without penalty.

However, the point of this paper is not to claim that live-in laboratories in themselves are an unacceptable research methodology. Instead, the aim is to highlight that an intimate intertwining of a research participant's daily and experimental life facilitates a problematic violation of established ethical norms. Experiments within living society raise the question of whether participants are able (and should be able to) withdraw. Yet, how can a participant withdraw from real life? This paper underpins the necessity for investigations into the normative boundaries of urban experimentation that affect human beings. In this last section, I want to briefly propose such a boundary: restrict live-in laboratory use to temporary residents.

Let's first explore the alternative solution: cover potential costs that withdrawing imposes on participants through compensation. For example, participants could be promised that if they withdraw, similar and adequate housing will be provided for them and that they will be assisted financially in the moving process. If we assume that all costs of withdrawing are

nullified through investigators' efforts, research participants would arguably not be penalized and influenced in their decision to withdraw from the LIP.

However, this strategy does have its downsides. Namely, it commits the investigators to the use of the LIP but leaves other potential problematic aspects of the experimental apparatus unresolved. For example, it remains unclear why it would be epistemically beneficial to have participants live for such a long duration in a laboratory setting. LIPs might also be problematic independent of their use, since by virtue of their design, they do not allow participants to realize their privacy.

A second solution does not face such problems. This strategy proposes to untangle the interwoven relations between a participant living their daily life and them being part of an experiment. By prohibiting investigators or participants from making a live-in laboratory a Lived-in Place – a permanent residency – and instead limiting their presence to temporary visits, like a Visited Place, many of the above-mentioned problems can be prevented. Participants would not need to worry about any negative consequences of withdrawing from the LIP since they could simply leave their human vivarium and go home.

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