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## Vulnerability in practice: Peeling back the layers, avoiding triggers, and preventing cascading effects

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### Abstract

The concept of vulnerability is widely used in bioethics, particularly in research ethics and public health ethics. The traditional approach construes vulnerability as inherent in individuals or the groups to which they belong and views vulnerability as requiring special protections. Florencia Luna and other bioethicists continue to challenge traditional ways of conceptualizing and applying the term. Luna began proposing a layered approach to this concept and recently extended this proposal to offer two new concepts to analyze the concept of vulnerability, namely understanding external conditions that trigger vulnerability and layers of vulnerability with cascading effects. Luna's conception of vulnerability is useful, which we demonstrate by applying her layered view and the new analyses in multiple contexts. We begin by outlining Luna's view and we use vignettes from healthcare involving transgender patients, the care of patients in psychiatric contexts, and research involving prisoners to illustrate how each part of Luna's concept elucidates important moral issues.

### Keywords

prisoner research; psychiatric ethics; public health ethics; research ethics; transgender healthcare; vulnerability

## 1 | INTRODUCTION

The concept of vulnerability is widely used in bioethics, particularly in research ethics and public health ethics. Florencia Luna and other bioethicists continue to challenge traditional ways of conceptualizing and applying the term. Luna began proposing a layered approach to this concept and recently extended this proposal to offer two new concepts to analyze

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### CONFLICTS OF INTEREST

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vulnerability, namely understanding external conditions that *trigger* vulnerability and layers of vulnerability with *cascading effects*. Luna's conception of vulnerability is useful, which we demonstrate by applying her layered view and the new analyses in multiple contexts. After our conceptual analysis of Luna's view, we use vignettes from healthcare involving transgender patients, care of patients in psychiatric contexts, and research involving prisoners to illustrate how each part of Luna's concept elucidates important moral issues.

## 2 | CONCEPTUAL ANALYSES

The proposal we defend in this article is an alternative answer to the traditional approach in which vulnerability is focused and defined by one's inclusion in a specific subpopulation. This traditional view considers racial minorities, persons with impairments and disabilities, pregnant women, and other historically marginalized populations as inherently and necessarily vulnerable. WHO-CIOMS 2002 provided an example of this vision, which provoked strong criticism at that time.<sup>1</sup> It is worth pointing out that the updated 2016 CIOMS/WHO guidelines incorporated changes based upon our recommended framework.<sup>2</sup> The traditional approach implies an essentialist view of populations. For example, research ethics assumes a baseline standard for a default paradigmatic research subject (a mature, moderately well-educated, clear-thinking, literate, self-supporting person) and assumes it is possible to identify vulnerabilities in subpopulations in opposition to the paradigm or as defaults of the paradigm. Several criticisms<sup>3</sup> can be levied against the traditional model; most notably, it defines people based upon stereotypes and overlooks contextual factors. This labels people in a way that cannot easily be avoided.<sup>4</sup>

In light of these criticisms, Luna proposes a different way of understanding the concept of vulnerability. She argues that vulnerability is relational and dynamic,<sup>5</sup> pointing out that it interacts with the context in which individuals are situated. Consequently, Luna suggests that we conceive of vulnerability not as consisting of labels, but as layers. These layers are multiple, related to the lack of consent, to socioeconomic conditions, age, gender, and so forth. Different layers may co-exist and they can be mitigated or minimized one at a time. Labeling people, as opposed to identifying internal and external conditions that trigger vulnerability, risks covering over conditions that need to be addressed and risks treating a class of people as inherently vulnerable when they are not. In addition, the layered view can also explain compounding vulnerability: how vulnerabilities interplay and render some persons more vulnerable than others similarly situated.

The layered proposal has been adopted by several feminist thinkers.<sup>6</sup> For example, Lange, Rogers and Dodds state, "What is needed is an approach that, first of all captures Luna's insight that vulnerable research participants inhabit a context generated by the coming together of layers of vulnerability."<sup>7</sup> Multiple theorists, individually and writing collectively, have accepted the layered approach; they opted to pursue other frameworks as they argued that Luna's account lacked practical application and concrete guidance.<sup>8</sup> In "Why bioethics needs a concept of vulnerability?" Rogers, Mackenzie and Dodds specify, "We also outline a taxonomy of different kinds of sources of vulnerability which we think is helpful in further specifying the layered approach to vulnerability advocated by Luna (2009)." In a similar vein, Lange, Rogers, and Dodds add: "Unlike Luna's, our approach gives concrete,

general guidance to researchers and research ethics committees.”<sup>9</sup> Thus, while these authors view Luna’s approach positively at the conceptual level, they point toward the need for more practical answers.<sup>10</sup> Considering these friendly criticisms then, in a recent article Luna<sup>11</sup> built on her concept of vulnerability as layers, arguing against the use of taxonomies and offering other practical solutions.<sup>12</sup> She began with the identification of layers, and then suggested we evaluate each layer by considering its risk of harm and probability of occurrence. This strategy outlines the normative force of harmful layers of vulnerability and, at the same time, offers concrete guidance. In that work, Luna went beyond the metaphor of layers and introduced two key concepts that have a practical and normative impact: triggers of vulnerability and layers with a cascading effect.

Triggers of vulnerability relate to the structure and way the concept functions. Layers of vulnerability are dispositions. Although other authors recognize this dispositional character of vulnerability,<sup>13</sup> they have not stressed the relevance of this feature in the deployment of the concept, nor the importance that this structure has in the triggering of vulnerabilities, nor its practical and normative force. As Luna explains, dispositions are “latent” until a stimulus condition triggers them. She uses the example of a cube of sugar, which has the dispositional property of solubility. Solubility happens only when the cube of sugar is introduced into a liquid. That event is its stimulus condition. It triggers solubility.<sup>14</sup> When evaluating layers of vulnerability, stimulus conditions (or triggers) are relevant features to consider as they make actual the disposition. Researchers, healthcare professionals, ethics committees, and policy-makers should identify the stimulus conditions that can trigger the actualization of a layer of vulnerability. Then, they should consider how probable that trigger is: if it is hardly probable that it will occur, it is less worrisome than if the trigger is highly probable.

The second key concept analyzes the effect that some layers can have. Such layers may generate new vulnerabilities or exacerbate existing ones. The relevance of this distinction lies in the normative force involved in harmful effects. Luna refers to these as cascade layers, named for the cascading effects that some layers of vulnerability may have.<sup>15</sup> Some examples of cascading effects can be found in the field of public health, such as those associated with pre-existing conditions or context-specific situations (for example, the lack of access to health services or the lack of protective labor laws can introduce new layers). Policies in the realm of public health can eradicate or at least minimize these cascading effects.

Once we have identified layers, triggers, and cascading effects, we should evaluate which are more harmful and probable. We should assess the harms, wrongs and risks involved in the different layers. These key concepts (stimulus conditions for triggers and cascading effects) help us to prioritize the relevance of some layers in order to try to avoid their occurrence. We should begin with the most harmful and move down to the less damaging ones. Our obligations are to eradicate, minimize, and not exacerbate vulnerability. To accomplish this, we should protect or foster the autonomy of the persons involved. Traditionally, when considering presumed vulnerability, the usual strategy was only that of protection.<sup>16</sup> Feminist thinkers—Mackenzie<sup>17</sup> as well as Luna—complement the usual strategy with that of fostering autonomy by seriously considering the importance of respecting persons and

their values. This can be achieved through various means such as education and providing access to needed resources.

In the following sections we will elucidate how viewing vulnerability as layers and identifying triggers or cascading effects can help researchers and practitioners to develop protocols and policies to identify and mitigate these vulnerabilities. We demonstrate the usefulness of these notions in healthcare involving transgender patients, patients in psychiatric care, and in research involving prisoners, using vignettes for each of these applications.

### 3 | LAYERS IN TRANSGENDER PATIENT CARE

Jefferson Pierce<sup>18</sup> is a Black nonbinary trans person in their late 20s. Pierce is having trouble getting the healthcare they need. Despite having a Master's degree, they have been unable to find employment in their field because they live in a U.S. state that does not have employment protections for transgender folks. Health insurance in the United States is strongly tied to certain types of jobs that Pierce has not been able to secure. Pierce moves in and out of insurance status and must prove eligibility for low-income safety net programs like Medicaid or for state subsidies to buy private health insurance. When asked their thoughts about seeking medical care, Pierce says, with a tone of dark humor: "Do I have to? Will I die if I don't? How much is this gonna cost me?"

Pierce receives new insurance, which assigns a primary care physician (PCP). Pierce is relieved because they've been having what seems to them to be tonsillitis or strep throat for the last year, saying "I guess it's time to figure this out, because I don't want to be sick anymore." Pierce goes to their assigned PCP and explains their symptoms. The PCP gives a depression screening, which accurately detects that Pierce is experiencing depression and anxiety; trans folks in general report depression and anxiety due to the way society treats them. The physician emphasizes that Pierce should seek behavioural health-care.<sup>19</sup> Pierce emphasizes that what they need is help with these recurring symptoms of throat infections: "...maybe if we get this situation fixed with my tonsils, I won't be so depressed, so sick and sad and tired everyday... I know I'm depressed... but what might help me is if we address my tonsils." In the course of the discussion, Pierce reveals that they are trans because the physician keeps trying to get them to take deeper breaths and, because it was the end of the day, the stiff and tight binder Pierce uses to achieve a flat chest was making it harder for them to breathe. The physician continues to ask questions about Pierce's trans status, including about their genitals. Pierce emphasizes that typically they can breathe just fine, but not when they've been wearing the binder for more than eight hours. Pierce leaves the office with no assistance for their recurring throat problems and a prescription for an inhaler. Their insurance may not cover a second visit to a different physician.

Transgender folks<sup>20</sup> are rendered vulnerable<sup>21</sup> by a variety of contextual factors that accumulate, compounding with devastating effect. Luna's conception of vulnerability is particularly useful for understanding both this layering effect and that vulnerability is not

intrinsic in trans identity but rather something that is done to trans folks. This occurs both with respect to social determinants of health—Pierce’s employment difficulties and unstable access to healthcare—and in the clinic. Note how Pierce’s physician focuses on Pierce’s trans status and on health concerns that stem from being trans in our society, giving Pierce a lot of medical attention but not the medical attention Pierce needs. Note also the points at which the provider ignores Pierce’s own expertise<sup>22</sup> on their trans non-binary embodied experience, resulting in both a misdiagnosis and what we call a missed diagnosis, where the provider misses the chance to catch an underlying issue.

Luna’s conception of vulnerability allows us to see all of these as layers that accumulate, rendering Jefferson Pierce and other trans folks vulnerable to poor health outcomes. It allows granularity in both our analysis and our solutions: we can look at the particulars of situations and ask, *how can we remove at least some of these layers of vulnerability?* This is only possible if we first come to see vulnerability as rendered, as layered, and then as removable layer by layer. *If the clinic can’t solve the social determinants, how can the clinic solve the clinician’s mis-steps? If we can’t get all clinicians to be well-prepared to treat trans folks, how can we change the system so that trans folks can access health care from clinicians who are well-prepared?* Vulnerability is made, and so it can be unmade.

Pierce’s case is a good start on understanding how trans folks are rendered vulnerable layer by layer, but there are other layers that can be remedied for which we must be on the look out. Some layers of vulnerability are rooted in a lack of basic information about transness. A transgender person is someone whose gender does not match their society’s gender norms for the sex they were assigned at birth. Trans folks include transgender men (men who were assigned female at birth) and transgender women (women who were assigned male at birth).<sup>23</sup> In the United States, trans folks may include nonbinary and gender-queer persons, like Jefferson Pierce, for whom the categories of “men” and “women” do not reflect their gender, and also gender-fluid persons, who may move between gender identities.<sup>24</sup> Gender is part of human identity and personal dignity. So, referring to trans folks—both when talking to them and about them—by the names and pronouns they choose is respectful. Refusing to call a trans person by their name, and instead relying on their birth certificate or other inappropriate documents, is called “deadnaming,” while using a pronoun or a form of address that does not match the trans person’s gender is “misgendering.” Deadnaming and misgendering indicate either active disrespect, or a lack of concern, for the trans person’s dignity and identity.

Though this terminological discussion may seem mere background, it is not. Trans folks are rendered vulnerable to harms to both dignity and identity when others mis-describe them in ways that dehumanize and objectify them or otherwise indicate a lack of concern. Trans patients may be deadnamed or misgendered by clinic staff, or may overhear clinicians talking about them as objects of curiosity or disgust. Clinic records and new-patient forms often only have “male” and “female” options for sex or, at best, a box marked “other.” This layer of vulnerability, in which clinic staff mis-describe a patient’s gender or forms require the patient to mis-describe their own gender, is only the first of many.

Such layers explain why participants in the Trans Health Ethics Project (THEP) responded to the question “What comes to mind when you think about seeking medical care?” with “anxiety,” “uncertainty,” “delaying,” “trepidation,” “embarrassing,” “rejection,” and “humiliation.” Such responses are common in larger-scale surveys of trans folks. Canada’s TransPulse survey found that 21% of respondents report having delayed seeking even emergency medical care.<sup>25</sup> Once they did go to the emergency room, 52% reported trans-specific negative experiences. Such experiences and delays are common in the United States and the European Union (EU), as well. The U.S. Institute of Medicine<sup>26</sup> found that 20% of trans folks report having delayed seeking preventive or general medical care such as pelvic exams, screening for sexually transmitted infections, and asthma care. Elsewhere, the EU Agency for Fundamental Rights<sup>27</sup> reports that 22% of trans people who accessed healthcare services in the prior year felt that healthcare personnel discriminated against them because of being trans. In a 2016 European survey of trans men and women, more than 25% reported that they had been refused treatment because a practitioner did not approve of gender reassignment.<sup>28</sup> Whether due to refusal by providers on the grounds of lack of training<sup>29</sup> or of prejudice, or due to patient-initiated delays based on fear of stigma, trans folks around the world are rendered vulnerable by not getting reliably good access to care.

Even when trans patients have stable health coverage and access to care, they can be rendered vulnerable in encounters with front-office staff. One THEP participant, a transgender man, reported difficulty when office staff were baffled by his attempt to make an appointment for gynecological services. Another THEP participant reported being told by a general practitioner’s office on the phone that “we don’t treat transgenders.” Both were rendered vulnerable by these avoidable responses from front-office staff, costing the patient more emotional labor to call and risk rejection by other offices and also resulting in delays in care. Front-office encounters can also go wrong if deadnaming or misgendering occurs, as described above, rendering patients vulnerable to harm from attacks on their dignity and identity, however innocently this may be done, for example out of ignorance. Office staff may deliberately enforce gender norms and refuse to use the patient’s name and pronouns, or they may be misled by medical records that only have binary sex entry fields. Multiple THEP participants reported that front-office staff’s gender confusion was audible to others in the waiting room: errors and corrections happen publicly, embarrassingly. Thus, the lines of confidentiality and privacy are blurred by such mistakes as well, which compounds the harm. When it comes to the front office, trans folks are rendered vulnerable by everything from the layout of forms and records to the behavior of staff.

Clinical encounters beyond the front office compound trans patient vulnerability through several avoidable deviations from non-trans patient encounters. Sometimes, the patient knows how a particular kind of exam should go, from before transition, but it does not proceed that way. One THEP participant, a transgender man who had not had any “bottom surgery”<sup>30</sup> and was attending a scheduled well-check, said: “Didn’t do any of that. Didn’t make me undress... didn’t do the abdomen [exam], didn’t do a women’s exam. And she stayed, like, seven feet across the room.” As this THEP participant said, it felt like “being kicked out of the human club. And when that happens routinely, and repeatedly, and in many different contexts, that’s harmful.” Refusal of touch is one layer of vulnerability that can apply to patients who are members of marginalized groups.<sup>31</sup> It is one of several clinician

behaviors that damages patient dignity and identity, and can cascade into misdiagnosis and missed diagnosis, rendering patients vulnerable to poor health outcomes as well.

Another such layer occurs when the clinician is so curious about this “rare opportunity” that the clinical encounter is “hijacked.” THEP participants reported being treated “like an experiment” and as “a chance for them to learn something.”<sup>32</sup> One THEP participant was asked about personal details unrelated to care, such as what “made” them trans. Another was asked whether their sibling still uses their deadname. This uses up scarce visit time for invasive questions that serve the provider rather than the patient. THEP participants reported that such visits often ended with their medical needs unaddressed, a pattern we also saw in Jefferson Pierce’s experience. Avoidable behaviors like losing focus on the needs of the patient in front of the clinician can render patients vulnerable to the harms of leaving clinical encounters with medical needs unaddressed.

A final clinician behavior that renders trans patients vulnerable to poor health outcomes involves the attribution of symptoms to transness, whether to being trans or to receiving transition treatments. In trans communities in the United States and the U.K., this phenomenon is dryly known as “trans broken arm syndrome.”<sup>33</sup> Of course, a trans patient’s broken arm needs just the same treatment as any patient’s. This manifested in the experience of a THEP participant who reported that their physician assumed that the swelling in their legs was caused by testosterone treatment—perhaps worth considering—but then refused to work up any alternatives until the patient went off “T” entirely, as though going off testosterone would not itself undermine the patient’s welfare. When this attribution of etiology to transness occurs, clinicians set themselves up to miss a diagnosis or to misdiagnose the patient, as well as to remove an effective treatment for another condition. This renders the patient more vulnerable in a cascading effect as many avoidable, undesirable consequences may follow.

Luna’s conception of vulnerability is an important lens for seeing how trans patients are not inherently vulnerable but are *avoidably rendered vulnerable* to poor health outcomes as well as to harms to dignity and identity, layer by layer, from the front office to the clinical encounter. If we see vulnerability in general—and trans vulnerability in particular—as monolithic or as fixed in identity, we will miss the fact that trans vulnerability is the outcome of changeable features of the world that can be addressed separately from one another. We need not fix the whole world of trans folks to begin the work of improving their health and dignity in clinical settings. Trans folks’ general welfare, the way we take their knowledge about their own bodies seriously, and their health outcomes can be improved by peeling back layers of vulnerability to eliminate them one by one, where we can. Vulnerability is made layer by layer, and so layer by layer it can be unmade.

#### 4 | TRIGGERS WITHIN PSYCHIATRIC CARE

Jolene Williams<sup>34</sup> has been married to her husband, Gerald Williams, for seven years. They live together in Arkansas, where Gerald works as a tax accountant and Jolene works part-time as a greeter at a retail store. Jolene just celebrated her 64<sup>th</sup> birthday, and she has been experiencing worsening arthritis and early signs

of dementia. She has no living family, and she relies on her husband's income and healthcare insurance. For several years, Jolene regularly saw an outpatient psychiatrist, Dr. Jones, who provided psychotherapy and antidepressants for her borderline personality disorder and chronic depression. Dr. Jones knew both Jolene and Gerald very well, but she recently moved to another state, referring Jolene to a colleague, Dr. Weston. Jolene felt uncomfortable meeting the new psychiatrist and canceled her appointment, and her prescription went unfilled as a result. After a few months of increasing tensions in their marriage, Gerald threatened to divorce Jolene if she did not start seeing Dr. Weston for, as Gerald put it, "all her crazy." Jolene's impulsive behaviour and alcohol consumption increased until she had an acute medical crisis that resulted in her being incapacitated in the local emergency department. This led to short-term psychiatric hospitalization, during which her husband served as the surrogate decision-maker for Jolene's treatment over her quiet objections but with her ultimate acquiescence. After this incident, Gerald began driving her to appointments with Dr. Weston over a six-month period. Jolene participates begrudgingly in psychotherapy, still not trusting the new doctor, and she does not agree with Dr. Weston's recommended change in prescription to an antipsychotic and does not fill any prescriptions from him. Dr. Weston documents that Jolene has poor insight into her illness, oppositional tendencies, and difficulty understanding her psychiatric needs.

Upset that Jolene continues to decline medication, Gerald calls Dr. Weston privately and requests that he prescribe his wife the antipsychotic medication. He tells Dr. Weston that he "can never know if what she's saying is true" because of her "delusions and lies." Dr. Weston says that he could explore the possibility of an antipsychotic medication again with Jolene, though Dr. Weston openly admits that he does not think she will be amenable. Gerald insists that Jolene's behaviour "has never been worse," and he suggests that Dr. Weston go ahead and fill the prescription, and Gerald can pick it up for her and put the medications in her food at home. Gerald says that he will have to change the locks on their house if she does not start improving.

In the above vignette, the layers of vulnerability are numerous for Jolene. For one, she has financial and social vulnerability due to her isolation and dependence on her husband's insurance coverage and income. This vulnerability may be related to her dementia or psychiatric conditions, but it may also be due to others' perceptions of her capabilities or her need for certain accommodations that employers are disinclined to provide. She also had a vulnerability to losing a trusted mental health professional, triggered when Dr. Jones left the state. Building therapeutic trust can be sensitive and challenging, given the parties' different epistemic positions and potential disagreement over therapeutic goals or modes of treatment. One implication of losing a trusted psychiatrist is losing access to medication refills, as occurred in this case. Jolene's underlying vulnerability to decomposition is then triggered, perhaps worsened by her husband's behavior and threats. Her reliance on Gerald becomes more and more evident as a source of vulnerability, given his threats to divorce and to lock her out of the house, which could leave her homeless, without healthcare coverage, and alone in a psychiatrically fragile state. What we see in this vignette is the



husband's increasing control over Jolene's care, culminating in his asking for permission to covertly medicate with the new psychiatrist's assistance (which is not necessarily illegal or professionally proscribed when patients are incapacitated with psychiatric impairment and dementia).<sup>35</sup>

It is unhelpfully simplistic merely to label Jolene as "vulnerable" due to her psychiatric conditions without attention to these contextual details and triggers. By identifying the layers of her vulnerability, what triggers them, their probability, and the level of potential harms, healthcare professionals and others can more accurately and respectfully address her vulnerability. For example, Dr. Jones may have been able to introduce Jolene to Dr. Weston before leaving town to help bridge the therapeutic relationship (and to help her find someone else if she did not want to continue with Dr. Weston). As a goal of psychotherapy, Dr. Jones may have also been able to help Jolene form additional social relationships or help Gerald and Jolene talk productively about therapeutic goals and treatment. Perhaps improvements in Dr. Jones's documentation in the medical record would have enhanced Dr. Weston's understanding of what Jolene *did* understand about her condition and treatment options, what she wanted to achieve in psychotherapy, and how to build trust with her. Even if the medication could provide some clinical benefit in terms of symptom alleviation, allowing covert medication at home would likely exacerbate Jolene's vulnerabilities and increase potential triggers by intensifying the power asymmetry between Jolene and Gerald, denying her agency, and deepening distrust all around. Given this, living at home with Gerald may need to be addressed in a therapeutic context where an outpatient social worker could help to identify community resources or other living options.

Persons with psychiatric disabilities vary substantially in terms of their symptoms, experiences of daily living, level of reliance on caregivers, and the layers of their vulnerabilities. Ableism pervades a range of institutions and interpersonal expectations and contributes to vulnerabilities that may be latent in some contexts and triggered in others. Ableism is "a system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity."<sup>36</sup> Widespread ableism impacts everyday living for many people with psychiatric disabilities, as when their perspectives or values are dismissed as "crazy." An instance of ableism can trigger vulnerability in an outpatient encounter, in a hospitalization, and in the pharmacy when picking up medications.<sup>37</sup> Persons with psychiatric disabilities are vulnerable to epistemic injustice, which occurs when a person is wronged as a knower and their testimony is immediately doubted as a result of systemic bias and prejudice.<sup>38</sup> Stereotypes and stigmas, implicit or explicit, feed misperceptions about the ability of their patients to meaningfully participate in identifying or pursuing appropriate therapeutic goals. Persons with psychiatric diagnoses routinely experience mistrust and pay unnecessary personal and social costs from widespread misperceptions about their dangerousness, unpredictability, and general competence.<sup>39</sup> It is against this backdrop that persons receive a psychiatric diagnosis.

Layers of vulnerability may be triggered by any number of factors, including (but certainly not limited to):

- diagnosis of a condition considered to be a serious and persistent mental illness (SPMI) or personality disorder;
- history of psychiatric hospitalizations or involuntary treatment;
- confinement in an acute psychiatric setting (involuntary or voluntary);
- active hallucinations or delusions;
- documented non-adherence in their medical or residential records;
- social isolation or housing insecurity.

All of these factors make it more likely that the person will experience harms of a significant magnitude and duration, making it substantially more difficult to, for example, find steady employment, maintain child custody, and guide decisions about their own housing and care plans. None of these points are meant to demonize psychiatrists or therapists—though there are important learning points for ongoing professional training to help mitigate and prevent vulnerability in the clinical relationship.

As one clinical example, consider the vulnerability of patients in capacity assessments.<sup>40</sup> In order to be authorized as their own medical decision-maker, a patient needs to show that they have decisional capacity—they need to demonstrate that they can sufficiently understand, reason through, appreciate, and communicate a choice.<sup>41</sup> Accurate capacity assessments are ethically important to ensure that the patient can make informed decisions that reflect their actual interests and values. Many people with psychiatric disabilities have capacity for all or most decisions.<sup>42</sup> There are a variety of ways in which capacity assessments can fail, however. The patient may be incorrectly assessed as incapacitated as a result of misperceptions about certain diagnoses, symptoms, or communication barriers. The healthcare professional (HCP)<sup>43</sup> might also miss important nuances to what the patient does and does not understand. The patient's capacity status could also fluctuate, but if the healthcare team does not notice those fluctuations or what precipitates dips in capacity, then the patient might not be empowered as a decision-maker when they are most capable. Vulnerabilities related to capacity assessments are exacerbated when physicians are inadequately trained, when time is too constrained for an in-depth interview, and when the patient's medical needs are acute. An inaccurate or imprecise assessment of incapacity can trigger multiple layers of vulnerability, since the patient would no longer be trusted as their own decision-maker.

Insight assessments may also end up triggering vulnerability. *Insight* refers to a patient's self-understanding of their condition. From the HCP's perspective, a patient with poor insight rejects their diagnosis, disputes pathological attributions to their behavior or affective states, and refuses treatment that the HCP believes is beneficial. If the HCP believes that the patient's poor insight makes it impossible for them to understand the basics of their medical needs, then the HCP may additionally have doubts about the patient's capacity status. The vulnerabilities that a patient could experience in relation to insight assessments therefore have similarities to the vulnerabilities of capacity assessments.<sup>44</sup> Multiple studies have found that HCPs consider poor insight to be a substantial barrier to their even attempting shared decision-making.<sup>45</sup> If the patient has been evaluated to lack insight, then

their vulnerability to epistemic injustice is heightened, since HCPs and others may be less likely to trust *any* of the patient's reports. Vulnerabilities related to insight assessments can be quickly exacerbated in clinical settings, especially since there are no standardized bedside tools for these assessments. Clinical documentation for insight assessments tend to be sparse, with a single word—“poor,” “partial,” “full,” and so forth.<sup>46</sup> This sparse documentation means that gradations and dimensions of insight can be easily missed and miscommunicated.

Studies over the years have shown that HCPs tend to have negative attitudes toward patients with certain diagnoses, especially personality disorders, and these attitudes manifest as doubts about treatment efficacy (therapeutic pessimism) and strong personal dislike.<sup>47</sup> Such a patient is vulnerable to being viewed as “hopeless.” There can be missed opportunities to provide benefits or address sources of harms or distress as a result. Instead of having a therapeutic alliance, the patient could experience increased isolation, and there is a risk of the HCP terminating their relationship. Patients in this situation may find it particularly difficult to find engaged and empathic care, which could contribute to internalized stigma, shame, and lost opportunities for shared decision-making.

The above analysis identifies layers of vulnerability and circumstances in which clinical environments are likely to trigger them. If HCPs recognize that the vulnerabilities commonly experienced by persons with psychiatric disabilities are not inevitable or inherent to the condition, they can better recognize opportunities for minimizing vulnerabilities in clinical encounters and across healthcare institutions.

## 5 | CASCADING EFFECTS AND RESEARCH INVOLVING PRISONERS

Dr. Silversmith has grant funding for her research on interventions to better understand and reduce the spread of Hepatitis C Virus (HCV) in prison facilities in the United States.<sup>48</sup> Dr. Silversmith has support from a state-run prison facility in a southeastern U.S. state that has agreed to be a partner in the research project, and is coordinating for the approval of the project with her university's Institutional Review Board (IRB). In her protocol description and consenting documents, Dr. Silversmith outlines the educational intervention, which will require a series of interviews and screenings from participants over the course of three years. The intervention is minimally invasive (blood sample to screen for HCV) and minimizes risks to participants by deidentifying the data to ensure that results are not traced back to specific subjects. In exchange for their participation, recruited prisoners will be provided with snacks and beverages during their initial screening, the follow-up focus group, and follow-up HCV screenings and qualitative surveys. Aside from the snacks and beverages, the participants will be entered into a monthly draw for a \$100 calling card. When discussing the protocol, the committee agrees that risks are minimal and benefits outweigh the risks. However, one member of the IRB raises concerns that the calling card may unduly influence some prisoners to participate when they otherwise might not. Specifically, they are concerned that the cost of calls from the prison is quite high; some prisoners might not be able to call family or friends and are willing to participate on the chance that

they will gain access to a calling card. Other members point out that the amount is not so high that it would coerce participation, and, unlike direct compensation or commissary funds/good, which might make participants targets if other prisoners come to know who wins the raffle, the calling cards can be spent only by the individual (the funds cannot be transferred to another prisoner and cannot be cashed in for money or other goods that might be coveted by others). No member of the IRB discusses whether the provision of drinks, snacks, or access to HCV screening should be considered compensation or a benefit of participating in the research.

According to the traditional view, prisoners as a group are inherently vulnerable, and the compensation Dr. Silversmith proposes would not *prima facie* be cause for concern. As members of the IRB have pointed out, risk of harm has been minimized and the identity of the raffle winner will be difficult to trace by other prisoners. Even if the raffle winner's identity is discovered, the calling card would not place the research participant in any danger since other prisoners could not access the funds or have the funds transferred to them. Shifting to Luna's framework, we can elucidate why the concerned IRB member might have good reason to ask questions about prison policy and call pricing when weighing whether the calling card compensation would unduly influence individuals to participate in the study.

As Luna and others building on her work remind us, vulnerability refers to the morally problematic disadvantaged placement of an individual within the context of social practices.<sup>49</sup> It is a common feature of the U.S. carceral system that all prisoners are subject to search without notice, must have permission to receive visitation or communication from family members or children (where in-person visitation is permitted), and are subject to a highly disciplined schedule. Consequently, all prisoners will have their self-determination undermined, but this foundational layer of vulnerability can be exacerbated by certain prison policies, leading to cascading effects in the life of specific prisoners. Ignoring context-specific and facility-specific conditions will blanket over the potentially cascading effects of such policies. This will, in turn, cover over the kinds of vulnerability to which incarcerated persons are subjected and the specific barriers to consent for participation in research. While it is the case that incarcerated life triggers specific vulnerabilities, different individuals within different incarceration settings will suffer cascading effects. When investigators seek to involve prisoners in their research, identifying the layers of vulnerability, triggers, and vulnerabilities that have cascading effects will be a crucial first step in mitigating harms and addressing concerns of undue influence, coercion, or exploitation.

Consider the fees for placing calls from a prison—any charge for calling may be considered an inconvenience, but the higher the fee, the more the fee will disproportionality affect some incarcerated persons. Many prisons charge far above the market rate, which disproportionality affects those who are economically disenfranchised.<sup>50</sup> In Mississippi, the price for a 15-minute phone call in a state correctional facility is \$15, and in Georgia the same length of time will cost an incarcerated person \$17.<sup>51</sup> Compare this to the newly passed law in Connecticut giving all incarcerated persons access to calls for free beginning in 2022.<sup>52</sup> In states where calling prices are exorbitant, if an incarcerated person has access to funds or has sufficient social support, even if the person is vulnerable to being economically disenfranchised because they cannot earn money while incarcerated,

this particular policy will not inevitably trigger a cascading effect resulting in harm to the individual's self-determination, familial bonds, or self-respect. However, if the prisoner has little financial support and little opportunity to earn money while incarcerated, this policy will trigger cascading effects causing harm before researchers ever enter the scene. Drawing out these differences requires that researchers identify whether, for example, prisoners have access to commissary funds, support "from the outside," or access to other work programs within the prison as an alternative means to earn money for commissary or call services. Doing so could reveal that even within the same prison there are different layers of vulnerability present in prison subjects, and conditions may have already triggered cascading effects. In such cases, incentives to participate in research that may enhance communication opportunities with researchers or friends/relatives outside of the prison may be coercive.

Now add to this assessment what the IRB did not consider—whether provisions of beverages, snacks and HCV screenings create or contribute to conditions of undue influence for potential participants. Consider additional prison policies that not only add a layer of vulnerability, but can trigger cascading effects for some prisoners. Such policies include the use of solitary confinement, food limitations, limitations of recreational outlets, limited or no access to routine healthcare services, and denial of a prisoner's sexual or gender identity. If prisoners have access to routine healthcare services, including HCV screening, then access to such services as part of a study would not be cause for concern on the part of the IRB. Similarly, if prisoners have ample access to food, including supplementary snacks and beverages outside of the prison-mandated mealtimes, then access to snacks and beverages (which may be of better quality than prisoners have access to normally, or, minimally, provide variation in their dietary choices) should not be considered influential on a prisoner's choice to volunteer as a study participant.

Additionally, consider specific vulnerabilities that might come from a researcher seeking information on a subpopulation of prisoners, such as LGBTQ+ individuals. Consider that LGBTQ+ prisoners face an additional layer of vulnerability: they are the target of increased violence and heightened conditions of oppression specifically because of their gender identity or sexual orientation. As revealed by a recent Bureau of Justice Statistics Report, sexual orientation was the single greatest determinant of sexual abuse in prisons in the United States.<sup>53</sup> These background conditions will mean that LGBTQ+ prisoners will likely face increased threats to their well-being that their heterosexual counterparts will not. Simply being LGBTQ+ in prison is a layer of vulnerability that, if known by other prisoners and prison staff, will have cascading effects that result in increased isolation (through the use of solitary confinement), increased scrutiny of behavior during visitation with family or friends, and increased threats of violence. We should expect more cascading effects and associated harms when a prisoner has dispositional layers as a result of their LGBTQ+ status, combined with poor socioeconomic resources, and high call fees (leading to increased isolation from social support from the outside). In such conditions, researchers will need to carefully evaluate whether such conditions provide reason to consider basic provisions such as snacks and beverages in a safe environment (since their everyday experience in prison is one of increased risk of violence and isolation, and being in a study with researchers would provide a reprieve) may directly influence a potential participant's decision to enroll in the study.

Tracking the cascading effects will help researchers to identify better and worse prison facilities to partner with when performing research with incarcerated populations, along with the specific conditions that different populations of prisoners face. Luna's concept of cascading effects allows us to bring to light the kinds of conditions that increase the likelihood of undue influence or coercion that might otherwise be missed, which is a step toward creating a system of responsible research involving prisoners. Though all incarcerated persons have limited liberty, the limitation on one's liberty does not, in itself, create coercion.<sup>54</sup> What this means is that researchers must take into account these different layers of vulnerability and how the triggering conditions of specific prisons and jails can cause cascading effects that need to be mitigated before enrolling subjects in research. This conception of vulnerability will likewise have ripple effects throughout the research process—from when researchers are drafting their recruitment protocols and IRBs are weighing risks and benefits, to how incentives are evaluated, and what appropriate consenting protocols look like. Such deliberations by researchers, IRBs, or research ethics committees can lead to the development of tools for tracking a more nuanced understanding of vulnerability.

## 6 | CONCLUSION

Luna's conception of vulnerability presents a valuable lens that can be used to guide practical actions in a variety of healthcare contexts. We have illustrated how the metaphor of layers powerfully demonstrates the ways in which the U.S. and other healthcare systems render transgender folks vulnerable, how layers of vulnerability within and circumstances where clinical environments are likely to be triggered within psychiatric care contexts, and the ways in which different prisons and jail policies in the United States can trigger cascading effects that researchers ought to mitigate prior to instigating research with prison populations. Taken together, we have elucidated how Luna's conception of vulnerability can be used to productively analyze how a wide variety of populations who are typically labelled vulnerable, as though the vulnerability were inherent within them, are better thought of as rendered vulnerable by the sedimentation of layers of vulnerability, triggering conditions that enact the vulnerability, and the cascading effects that can trigger multiple layers of vulnerability at the same time, resulting in increased harm. Seeing vulnerability as layered in this way can help us to remedy vulnerability by changing behaviors and policies, peeling back the layers bit by bit wherever any of us—including those who are rendered vulnerable—can do so.

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## Biographies

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**Florencia Luna** MA PhD, is Principal Researcher at CONICET (National Scientific and Technological Research Council), Argentina. She was Director of the Program of bioethics at FLACSO, Argentina, and President of the International Association of Bioethics (IAB) (2003–2005). She is an Expert for the World Health Organization (WHO) and was a member of the Scientific and Advisory Committee (STAC) of the Department of Tropical Diseases Research (TDR) at WHO (2011–2016).

**Laura Guidry-Grimes** is Assistant Professor in the Department of Medical Humanities and Bioethics, with a secondary appointment in Psychiatry at the University of Arkansas for Medical Sciences (UAMS). She serves as a clinical ethics consultant for UAMS Health and Arkansas Children’s Hospital. Her research focuses on vulnerability in clinical settings, psychiatric ethics, and disability bioethics.

**Alison Reiheld** (PhD Philosophy) is Professor of Philosophy at Southern Illinois University-Edwardsville (SIUE) and formerly Director of Women’s Studies at SIUE. She has studied, researched, taught, and rounded in medical ethics for over two decades. Dr. Reiheld’s work is varied but bound together by concerns about power and ethics in contexts ranging from memory to civility to the clinical treatment of a variety of social groups in clinical settings ranging from general care to obstetrics and gynecology. She has written on the ethics of memory, conceptual and bioethical issues with miscarriage, anti-obesity public health campaigns, and more. Dr. Reiheld recently completed a series of interviews with transgender folks on their experiences of seeking healthcare as part of the Trans Health Ethics Project.

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