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**The Overlooked Risk of Intimate Violation in Research:**

**No Perianal Sampling without Consent**

Jasmine Gunkel (National Institutes of Health)

There are few moral principles less controversial than “don’t touch people’s private parts without consent.” Though the principle doesn’t make explicit that there are exceptions, there clearly are some. Parents must wipe their infants. If an unconscious patient is admitted to the emergency room with a profusely bleeding laceration on their genitals, a doctor must give them stitches. The researchers who proposed the study in question (case citation), which would look for a connection between burn patients’ microbiomes and their clinical outcomes, presumably believed they had identified an additional exception to the aforementioned principle. I argue that they did not. Rather, because of their tremendous inherent risks, we ought only to perform *intimate* procedures on those who can’t consent when the procedure is for their own good.

Intimate violations have been overlooked in both philosophy and medicine. Because of this, we have lacked an adequate conceptual framework for identifying certain kinds of harms research can inflict. When we understand these special risks, we see that the IRB was right to deny a waiver of consent.

**Case and Regulations Background:**

To understand the full trajectory of patients’ microbiomes over the course of burn treatment, researchers wanted to collect samples from patients as soon after admission as possible. While the study would not benefit those patients, the knowledge gained could be tremendously valuable to future patients. If researchers can identify changes in microbiota associated with poor health outcomes, we have another tool to identify earlier those at most risk. The research could put us on a path towards discovering novel therapies, ones that seek to alter burn patients’ microbiomes.

However, the population of study, those with burns covering 20-60% of their body, enter emergency rooms in need of urgent, significant medical care. Burn injuries are exceptionally painful (Patterson et al 2004). Some burn victims enter ICUs unconscious, and even if patients are conscious, tremendous pain is often incapacitating. Given this, the researchers concluded (correctly, in my view) that getting consent for swab-collection at admission was “impracticable.” So, researchers asked for a consent waiver for the first collection, which would include having a swab “brushed over the perianal area for approximately 15 seconds.” They argued that this touching was ‘commensurate’ with the routine touching done by nurses while cleaning patients.

When a study offers no prospective benefits to patients, federal regulations require that waivers of consent be approved only if the study entails no more than a minimal increase in risk (45 CFR 116 f 3).[[1]](#footnote-1) It was clear to all parties that the study offered patients no prospective benefits. What is contested is the level of additional risk the study subjected patients to. In what follows, I argue that it certainly exceeded the minimal risk threshold.

**Intimate Violation and its Risks**

Though a stranger’s touching our arm and touching our butt can both infringe on our bodily autonomy, there is something distinctly violating about the latter case. It is an *intimate rights* violation. We must understand what makes for an intimate violation, and why they are so significant, if we are to understand the gravity of the risks faced by patients.

Though most of us seldom explicitly invoke intimacy, an intuitive concern about it runs through many discussions of patient protections. The IRB was attuned to the distinctive potential of the perianal swabs to cause emotional distress in patients. This distinctive potential is due, I believe, to the intimacy of the swab collection. In getting down to a foundational understanding of intimacy, we are positioned to identify less obviously intimate procedures, and ensure adequate protections. By making intimacy explicit, we can better use it as a tool for evaluating risks.

Exposure of a person’s ‘intimate zones’ carries substantial moral risk. As I argue elsewhere, our intimate zones are features we’re disposed to hide, and feel psychological discomfort at the prospect of exposing to the public. They’re also features that are importantly connected to our identity. We believe, fear, or worry that they reveal who we are. Given this, we’re particularly liable to feel shame about our intimate zones, and shame about them is liable to shape us in significant, person-altering ways (Gunkel 2023, Gunkel 2024).

It’s easy to see how our aptly named “private parts” typically meet these conditions. Most of us would be very uncomfortable walking down Main Street without bottoms on. It’s not only because we’d be afraid of arrest, but because there’s something scary about having everyone’s gaze on these parts of ourselves. Even disrobing in a doctor’s office is tremendously uncomfortable for many. And people do commonly see these parts as being importantly connected to who they are. They worry about how they look, smell, or perform. They believe they’re part of their sexuality, or fear they render their person unattractive. And though we hope medical professionals are looking at us clinically and nonjudgmentally, their touch can still inspire impactful worries and fears.

Given all the self-consciousness that exists about private parts, we know that some patients might feel self-conscious about having people investigate the organisms that live on theirs, that contribute to their smell and their health. The collection of data about one’s private parts can inspire fear, worry, and shame beyond what the touch itself would inspire. The touch passes, but the data lasts. The patient might anxiously wonder what a researcher is gleaning from the data taken from their private parts. They might worry about inferences that can be made about how they smell, they might fear their perianal area is “gross,” that they are “gross.”

While the physical actions taken for cleaning and sample-collection are not dissimilar, their purpose is different. One is undertaken for the good of the patient, the other to gain scientific knowledge. Someone does not violate us when they touch our intimate parts because it is necessary for our wellbeing. But the same touch can be violating when done for a different purpose. A nurse may not continue to touch an unconscious patient’s genitals when they no longer need cleaning, even if those touches are physically identical to the necessary ones. It is obviously wrong if done for their own gratification, but it is also wrong if done to secure goods for others.

We must anticipate that some patients will feel discomfort and shame about having their perianal areas touched while unconscious. We, tragically, must subject patients to these intimate risks when it’s required for their own care. It would be worse *for the patient* to risk infection. But that we may clean unconscious patients’ private parts does not entail we have permission to touch these areas for other purposes, especially when the purpose might elicit additional distress and shame.

Given uncertainty about how a particular patient will feel about perianal collection and the potential for intimate violations to cause significant, person-altering harm, we should err on the side of patient protection. “Don’t touch people’s private parts without consent” is a widely accepted moral rule for good reason.

**Disclaimer**:

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1. Morality, too, requires this (Largent et al 2010). [↑](#footnote-ref-1)