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Informed Consent and Comprehension after the Pragmatic Turn

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INTRODUCTION

In their article, Clapp et al. call for what we describe as a *pragmatic turn* in bioethics (Clapp et al. 2025). They outline limitations imposed on the field by its historical, common-sense commitment to a "representational" ideology that focuses narrowly on the semantic content of healthcare interactions while erasing or downplaying the roles of social indexicality, evidential presuppositions, and status negotiation effectuated through linguistic practice. As the authors note, bioethicists have traditionally analyzed what we do with words by focusing on what those words convey, on their propositions about the world. By drawing our attention to the pragmatics of communicative events, the authors propose to broaden the approach, enabling a robust, empirical understanding of linguistic materials as well as a more grounded and responsive normative analysis.

As a linguistic anthropologist (CMEH) and a philosopher and behavioral researcher (PHS), we wholeheartedly endorse the authors' call for a pragmatic turn. In this Commentary, we elaborate their argument and analyze its implications by applying these methods to our own data on informed consent, extending early work (Manson and O'Neill 2007). In so doing, we contend that the traditional, representationalist privileging of comprehension fails to capture informed consent's critical, pragmatic role in supporting trust, acknowledging agency, and improving relational dynamics. We argue not that comprehension should be dismissed as insignificant, but instead that the social consequences of disclosure may have equally critical implications for its ethical appropriateness.

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CONSENT IN GENETIC COUNSELING

Genetic counselors (GCs) sometimes jokingly refer to the educational preamble to their consent practice as their "central dogma" (Halverson 2017). In its fullest form, the dogma begins: "Your body is made of trillions of cells, and inside those cells is a nucleus, and inside that nucleus are usually 23 paired chromosomes…" It may continue with an acknowledgement of nucleotides, amino acids, types of variation, and their impact on human health. Such disclosure can certainly be a mouthful! In Halverson's study of consent for genetic testing, many GCs apologized breathlessly afterwards: "I'm sorry; I feel like I just vomited a lot of information on you." The GCs' assessments of patients' consequent comprehension were likewise met frequently with bewilderment: "It's all Greek to me," one cancer patient responded.

So why did GCs go through the dogma in the first place if comprehension was either limited or nonexistent? Certainly, they varied their preamble and attempted to fit it to the health literacy and interest they perceived in their patients, but the dogma was standard fare in some form, even where it appeared to make no contribution to understanding or the patients' ability to express their autonomy. Nonetheless, when Halverson asked the GCs, they held firm that the disclosure was ethically necessary. It was important, Halverson was told, that patients understand at least some subset of the science they were describing. It was *dogma,* after all.

But when confronted with the widespread lack of comprehension, the GCs uniformly waffled. "At the end of the day," one of his interviewees clarified, if somebody wants to consent, are you really going to deny them testing, even though you've explained it and they think they've got it, but we think they don't? I've never actually seen somebody say, 'No, I'm not going to let you sign this form to have your blood drawn.' Now, that being said, if [a patient is] saying those things where it's just blatantly obvious they're not understanding what the test is or what's being done, you know, I would probably still let them consent, but I would normally try and circle back, although you can spend four hours with somebody and they still not get it.

Her moral intuition was that disclosure was necessary and comprehension ideal. But the risks of the blood draw and subsequent sequencing were too limited to require even basic comprehension of the central medico-scientific facts.

We agree with this everyday ethical analysis and stress that it relies on an unstated but definitively *pragmatic* ideology of informed consent. While technically complex, the practice of explaining the "central dogma" was often lighthearted and engaging. It transformed participants' interactional statuses, their differential and dynamic commitments and entitlements to behave and interpret in specific ways. Halverson was regularly told in interviews with patients that they appreciated the education regardless of their limited uptake. Through the disclosure, they came to think of their GCs as intelligent, supportive, and kind. They believed they could defer to their GCs' expertise and–most important for the current analysis–that they could trust their recommendations.

CONSENT FOR BIOBANK RESEARCH

Kasperbauer, Schwartz, and colleagues have found similarly striking results on the ethical role of comprehension in their work on biobanking consent. The research team conducted knowledge tests and in-depth interviews with biobank participants to assess their knowledge of the program into which they had recently enrolled as well as their attitudes toward understanding as a criterion for that enrollment. From a referentialist perspective, the results were worrisome: On average, biobank enrollees correctly answered only six of eleven true/false questions (Kasperbauer, Schmidt, et al. 2021), each of which had been vetted for readability and deemed critical by experts in the field (Beskow and Weinfurt 2019). These scores were even lower than those of a previous study by Beskow and colleagues (Beskow et al. 2017), who had recruited from the general public rather than actual enrollees. Kasperbauer and Schwartz (2019) argued that comprehension of biobanking practice may therefore be "even more challenging in a real-life situation."

In interviews, Schwartz's participants–like Halverson's genetic counselees–understood biobanking to be a low-risk activity, and comprehension therefore appeared to them to exert only a limited influence on the ethical validity of their consent. Most of Schwartz's biobank enrollees and the experts impaneled in Beskow's study considered knowledge of only a subset of information to be necessary. In contrast, other experts in Beskow's study and some commentators responding to her paper in *AJOB* (e.g., Appelbaum 2019) argued that limited understanding is not consistent with ethically valid consent. Their position, in Clapp and colleagues' terminology, focuses narrowly on the representational content of the consent documents. Such analysis, though, ignores other features of these texts, which play key ethical roles as well. In particular, Schwartz's biobank enrollees saw in the informed consent process the establishment of a relationship with the biobank, making donors into gift-givers and researchers into recipients. From their perspective, requiring candidates to pass a knowledge test violated their relational status. A representationalist focus on comprehension would fail to countenance the ethics of the status transformations effected by the speech act of consent, something well clarified by the pragmatic turn.

Schwartz's participants also explained that they relied on their trust in the recruiting institution as a heuristic for their decision-making (Kasperbauer et al. 2022). Once again, it is fruitful to attend to the pragmatic implications of the interaction, above and beyond its representational content. The enrollees viewed the speech act of consent to be felicitous in part due to seeing it as their partnering with a trustworthy institution, i.e., as a dynamic feature of their relational status rather than as a semantic feature of either disclosure or comprehension. And this insight–made available by the pragmatic turn–explains why enrollees so frequently missed a particular question on the knowledge test: Only 8–12% of participants answered correctly that their genetic and health information would be shared with third parties outside the biobank. Interviewees indicated that their answer was based on their belief that a "trustworthy" institution would never share their information with third parties (Kasperbauer, Halverson, et al. 2022). The challenge here appears to parallel Clapp and colleagues' analysis of the grading of surgical risk: While lay participants and biobank governance committees referred to entering a trusting relationship, the construct indexically presupposed different cultural models of how entities in such a relationship stereotypically

should and do behave. Participants relied on these presuppositions in their decision-making rather than what was explicitly stated in the consent form. Understanding how they saw their relationship to the recruiting institution helps to explain an otherwise puzzling aspect of their linguistic practice and performance on the knowledge test.

CONCLUSION

Informed consent cannot be understood narrowly as a cognitive achievement of sharing representations between minds (Manson and O'Neill 2007); rather, we must analyze it in its full pragmatic context. The informed consent process functions as a negotiation of statuses that builds trust and agentive capacity even when it fails to improve content knowledge. As we have seen, research participants, clinicians, and even bioethics experts may view decisions based on trust and those based on understanding as equally ethical and equally valid. Expanding our focus beyond semantics to include the pragmatics of such speech acts fosters an analysis of informed consent that more accurately comports both with empirical work on its relational features as well as with its normative dimensions.

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