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From Knowing to Understanding: Revisiting Consent

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Dickert et al. (2020) effectively address how factors such as time limitations, stress, and illness severity in acute conditions warrant a deeper evaluation of how current consent processes serve patients. While data suggests that patients "prefer to be asked for permission upfront rather than waiving consent" (7), consent forms themselves "are frequently long and technical, follow rigid templates, and contain language that appears to prioritize institutional protection" (7). Such findings elucidate patients' valuation of personal agency over settling for the "benefit of the doubt" that physicians and the consent forms they provide are acting in the patients' best interests. In response, the authors recommend revisions to consent forms in terms of content, structure, and tone to better facilitate patient understanding beyond the mere conveyance of information. We aim to build on Dickert et al.'s discussion of how "consent processes serve functions beyond facilitating an informed, autonomous decision" (7), but with a broader focus on an under-recognized purpose of the consent process: namely, reaffirming a patient's status as a capable, rational agent. Specifically, we argue that patients can exercise this agency when they thoroughly understand the consent process, per Grimm's (2012) conception of understanding.

For Grimm, mere propositional knowledge, or "knowledge that something is the case" (105), does not entail understanding. He offers the following illustration: "it seems that someone could have the propositional knowledge that his house burned down because of faulty wiring (because, say, he learned this from the reliable fire chief on the scene), even though he fails to understand why his house burned down because he fails to see how the faulty wiring might give rise to the fire" (106). This distinction between understanding and mere knowledge is mirrored in Dickert et al.'s discussion of consent forms, wherein "PAP members felt that both long and technical forms were likely to overload time-crunched and stressed individuals with information that is difficult to understand or unlikely to be related to participation" (9). Here, the consent forms Dickert et al. discuss represent what Grimm describes as "information chunks" (105), parts of a scaffolding-like complex the mind grasps when it understands, but mere knowledge of which is not sufficient for understanding. When consent forms employ technical jargon or overload patients with information, they make it difficult to determine the most important parts of a complex and how these parts relate. They, therefore, fail to present information in a graspable manner. This yields patient uptake which is either (1) incomplete or (2) an inaccurate reflection of the world. Subsequently, these factors threaten to undermine the rational agency of patients' decision-making process.

In addition to Dickert et al.'s suggestions for consent form revision, we posit that a patient's rational agency can be protected in this revision process by focusing on two facets of understanding identified by

Grimm: (1) the superior ability of understanding to reflect/mirror the world, and (2) the superior status of understanding as an intellectual achievement.

Whereas propositional knowledge provides abstract or isolated pieces of information, an accurately constructed and grasped complex provides a more complete view of reality's interdependent parts. Understanding allows an individual to apprehend how "various elements of the representation or model are related to one another" (Grimm 2012, 107), thereby allowing deeper engagement with their reality, compared to propositional knowledge. Patients in Dickert et al.'s research perceived the information complex presented by consent forms as inadequate and lacking interdependence between parts; they suggested the consent form structure lacked "logical sequence," was "choppy," and was difficult to follow in real-time. This suggests the presentation of information in traditional consent forms can result only in assenting to a proposition—a direct contradiction to the agent-driven informed consent desired by Dickert et al. (Grimm 2012, 110).

Second, Grimm situates understanding as an intellectual achievement which is superior to mere knowledge. Grimm states, "Unlike knowledge, which can simply be 'given' to you by a reliable testifier, understanding always seems to require some sort of significant cognitive work on one's own end [such that] any success that results will always be primarily attributable to the abilities of the agent coming to understand, rather than to anyone else" (111). Understanding is a cognitive achievement grounded in the unique capabilities of the individual. The patient who understands is thus an active participant as a rational agent, not merely a passive recipient of knowledge. Dickert et al. address the importance of this aspect of understanding in their criticism that consent form features such as lengthiness, technicality of language, and "rigid templates" (7) problematically convey a "one size fits all" approach to consent forms, leaving little room for or even impeding the sort of personalized cognitive work necessary to constitute an achievement of understanding.

As a response to these limitations of the consent process, we recommend as one possible remedy an approach to consent which promotes patient understanding by incorporating interactive smart-technology media. Procedures for such an approach would include the introduction of consent-relevant information via an interactive tablet program. This would require patients to navigate using touch in response to on-screen prompts, sounds, and video segments. Patients would then be encouraged to revisit the program throughout the trial/treatment alongside friends, family, and their clinicians.

While this approach remains novel, recent work has supported similar approaches in children's research. For example, Mayne et al. (2016) advocate a movement away from adolescent consent as a formality, toward an interactive smart-technology model which establishes adolescents as rational agents "by enabling young children to understand what their participation means" (14). This recommendation grows out concerns shared with Dickert et al: for example, concerns about how consent form lengthiness and overly clinical language hampers patient understanding, as in the PAP members' assessment that many patients are lay-persons who "lack the requisite 'medical knowledge to sort through the mud'" (9).

In Mayne et al.'s approach, information is presented to adolescent patients through a storybook read via a computerized touch-screen. The authors state, "interactive technologies such as a 'touch-screen' and sound effects can be utilized to enhance the child's engagement with the story" (11). This engagement encourages what the authors refer to as "playfulness" (13), a form of receiving consent-relevant material which is both positive and participatory. In requiring that participants grapple with a "sense of overcoming obstacles" (Grimm 2012, 111), we believe this process exemplifies the kind of task completion that counts as a cognitive achievement facilitating understanding and also provides a guide to what a smart-technology consent program for adults might look like.

The smart-technology approach to consent can also allow for mutual engagement on behalf of the patient and clinician, which can bolster the rational agency of the patient. As Mayne et al. write, "visual representations combining images and texts can promote understanding, encourage researcher/child discussions, [and] provide opportunities for children to practice decision-making" (9). We likewise believe that in adult patients, interaction with a smart-technology consent program could satisfy what Dickert et al. highlighted as patients' desire for consent forms that "mimic an effective conversation" (15), and that could, in turn, stimulate further conversation between patients and clinicians. Furthermore, allowing patients to keep the tablets for the duration of the trial/procedure could aid patients in solidifying understanding by reviewing consent information, recounting information to friends/family through what Mayne et al. call "cycle telling" (14), and offering patients the opportunity to revisit terms of consent with their clinicians. This open-ended relationship presented by the smart-technology format reimagines consent as a renegotiable, ongoing process, which not only ameliorates the stress of time-restrictive decision-making, but also reaffirms patients' statuses as rational agents.

Finally, Mayne et al. point out that such technologies are conveniently programmable to support diversity, and "can be adapted to meet the varying needs of children […], and is particularly suitable for pre-literate or indigenous groups whose culture is strongly story- or image-based" (12). When applied to an adult population, this feature of interactive smart-technology may, therefore, help address the "one size fits all" issue which Dickert et al. address.

Of course, certain limitations will need to be addressed to implement the kind of smart-technology consent process we've outlined: a lack of comfort or familiarity with smart-technology in some populations; the technical issues that accompany the adoption of any new technology; novel privacy and confidentiality concerns that are raised by the process; the additional time burden on patients; and so on. We believe, however, that despite these limitations, the smart-technology approach offers promising possibilities for bolstering understanding among patients and thereby addressing the issues raised by Dickert et al.

References:

Dickert, N., et al. 2020. Partnering with patients to bridge gaps in consent for acute care research. The American Journal of Bioethics 20(5): 7–17.

Grimm, S. 2012. The value of understanding. Philosophy Compass 7(2): 103–117. doi: 10.1111/j.1747-9991.2011. 00460.

Mayne, F., C. Howitt, and L. Rennie. 2016. Meaningful informed consent with young children: Looking forward through an interactive narrative approach. Early Child Development and Care 186(5): 673–687.