To Protect “Vulnerable Populations,” or to Address “Vulnerabilities”? Towards a New Paradigm in Human Research Participant Protections
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Public Health

Submission Type: Scientific
Topic Area: Ethics & Risk
Poster Number: 101

Problem Statement: In Research Ethics, “Vulnerable People” and “Vulnerable Populations” are given huge importance. Historic reasons for this importance are indeed valid and have shaped significantly our current debates in advancing ethical research. However, even amidst calls every now and then for increased protections for vulnerable populations, a growingly significant segment of bioethics scholars argue otherwise; some even maintaining that the whole concept is futile in HRPP. I explored the reasons behind these controversies and examined whether and how the concept of vulnerability can be useful in HRPPs in the 21st century. If we examine from a systems science perspective, we can see an important aspect in protection of vulnerable populations as addressed in many bioethics deliberations, especially in ethics of biomedical research; that its either very superficial and tokenistic, if not paternalistic. Guidelines, regulations, publications, and often research ethics reviews tend to focus the discussions towards pre-categorized groups called “vulnerable populations” or “vulnerable categories” of research participants rather than the different types of vulnerabilities of individual participants in their environments. On one hand, a lot of research participants with vulnerabilities tend to be overlooked since they do not belong to these pre-categorized groups. Secondly, just because potential participants “belong” to such groups, we tend to overprotect them – for example, women, children, elderly, etc. While the former situation can lead to the argument that every research participant is vulnerable, the latter situation denies the benefits of research from some groups in the name of their protection. Both these arguments tend to defy the usefulness of this important concept in HRPP.

Additional Information: Moving our focus away from “vulnerable populations” and addressing potential “vulnerability factors,” can overcome this paradox. This is explained using a conceptual diagrammatic model of consent, which shows how prospective participants decide to participate or not based on their relative perceptions of risk and benefit. Different vulnerability factors of an individual can have varying degrees of push-pull effects on the risk-benefit perception threshold of this decision making model. Educating researchers and HRPP professionals using this model ensures that the concept of vulnerability is still useful in HRPPs. However, the paper also lists limitations of this model at this conceptual stage. A key factor in understanding these factors and ways to address them is community engagement. Drawing from this conceptual model, HRPP professionals, bioethicists, and others must undertake empirical research on vulnerability factors, through community engagement.