

Opening the gate to empower patients

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ABSTRACT

Introduction/Background

Gaining access to research participants is often fraught with difficulties. When the proposed participants are considered vulnerable, access issues can multiply exponentially. Ethics committee and health professionals frequently take on the role of gatekeeper, intending to protect potential participants from the perceived harms of participating in research. Yet, there is little evidence that engaging in research poses risks to vulnerable participants. Although well meaning, making decisions on behalf of patients is paternalistic, disempowering patients and robbing them of their right to autonomy, to decide for themselves whether to participate. We argue that nurse leaders should carefully consider the potential benefits to patients when they are considering whether to present research invitations to them.

Aim/Purpose of the project

The aim of this systematic review was to review studies that discussed the experiences of vulnerable populations participating in research.

Methods

The review was conducted according to PRISMA guidelines. After screening and review, 31 articles from thirteen databases were critically appraised via the Critical Appraisal Program (CASP) toolkit and Effective Public Health Project (EPHPP) tool, leaving 11 articles to be synthesised narratively to identify common themes.

Results

Despite some reports of distress, responses from participants were overwhelmingly positive. Even those who did experience some level of discomfort mostly stated they would participate in future research. Three major themes were extracted: "It was worth it"; "Even if it hurt, I would do it again"; "Risk or benefit: fixing the location on the continuum".

Conclusion

There is minimal evidence of harm to vulnerable participants engaging in research. On the contrary, there is evidence of benefit for participants and evidence that they are willing to participate if given the opportunity. Gatekeeping is paternalistic and can further marginalise vulnerable populations by denying them the benefits to be gained from research designed to optimise their health outcomes.