

## NURSES: AN UNTAPPED RESEARCH ETHICS RESOURCE

Nurses play fundamental roles in the ethics of health research, although often the roles of those who are not principal investigators remain largely invisible. Nurses are also members of research ethics committees, are research assistants and study coordinators, and most important, provide care for patients who are enrolled in research studies. This invisibility may lead to a lack of appreciation of the knowledge nurses have with respect to protecting research participants and a lack of specific guidance given to them in codes and standards of research ethics. Exploring nurses' insights into how research participants could best be protected is a fruitful area of research, especially in hospital-based clinical research, that has yet to be fully realized. Furthermore, the input of nurses has not been sufficiently drawn on in the continuing ethical monitoring of studies or the development of research ethics standards.

Nurses' often prolonged proximity to patients, along with their education which prepares them to attend to the whole person, may provide them with excellent insights into how to best protect research participants. Because the risks and benefits of research are ideally comprehensively described in a way that takes into account not only physical aspects, but also emotional, social, legal and political ones, nurses' perspective can be highly valuable. The concerns nurses have expressed regarding patients in research illustrate some areas of nurses' moral understandings with respect to research ethics and participant protection. The author<sup>1</sup> has identified six of these nursing concerns including:

1. Participants do not always understand that research goals and clinical goals are not the same.
2. Participants at times would like to withdraw, but are being compelled to stay in a study.
3. Suffering patients may not be fully aware of the alternatives to being in a study, such as palliative care.
4. Participants may initially enroll in a research study with decision-making capacity but later may become incapacitated to the extent that they are no longer capable of on-going consent.
5. Nurses can become aware of the potentially unethical behavior of researchers.
6. Substitute decision makers may be making decisions that are not in the best interest of participants.

Some of these concerns relate to the informed consent of research participants, especially in clinical research. As an ethical norm, informed consent entails the voluntariness of consent, the capacity of participants (or their substitute decision-makers) and requires adequate and understandable information of the study, including its risk and benefits, be provided. Nurses may have a heightened awareness of the practice of informed consent far beyond the codification of it as an ethical standard which could contribute greatly to the enterprise of research ethics. For example, nurses, through the relationships they have with patients and their families, may know that although a dying patient has agreed to participation that she does not know that she is unlikely to benefit directly from the research, but is instead likely only to experience the side-effects of a treatment. This recognition might not be apparent to the person enrolling the patient if she has never worked closely with dying people. Understanding better how to assess potential participants for their understanding of research and its goals, would benefit from nurses' insights regarding this matter.

One aspect that is not mentioned is that it is also possible to overprotect patients as potential participants also<sup>1</sup>. Nurses have a long history of identifying the strengths of people in their care. While it is necessary to recognize that all people have vulnerabilities, some groups of people may be deemed 'vulnerable' as a category, such as older people, even when they have the strength and resilience to consent to research.<sup>2</sup> Here again, nurses could contribute to a better understanding of practices that unintentionally perpetuate paternalism as the result of stereotyping. Better, more nuanced, assessments of capacity and the ability to reflect on assumptions, could better foster social justice and promote forms of research that could benefit a wide array of people.

Nurses can also often be positioned well to contribute to the ongoing monitoring of research after research ethics approval has been obtained and the study is underway. While informed consent is often practiced as though it is one moment in time when the consent form is signed, ideally it is ongoing. Researchers, unlike nurses, may not be aware that a hospitalized participant is no longer capable or perhaps needs additional or repeated information. Beyond informed consent, nurses could be better involved in ensuring that approved protocols are followed. As identified, nurses can become aware of the unethical practices of researchers which is not surprising given their closeness to patients who might be participating in research.<sup>1</sup> To date, however, little is known about how nurses contribute to ongoing monitoring.

While it has now become generally understood that nurses conduct research, the potential role of nurses in research ethics is almost never described nor do they tend to be involved in the development of research ethics standards. The positioning of nurses in healthcare, with their often deep involvement with participants, is a resource that needs to be made visible and valued. Ultimately, it may be the role of nurse researchers to make this evident to the research community.

## REFERENCES

1. Grace P. Nursing ethics and professional responsibility in advanced practice. 3<sup>th</sup> ed. Burlington, Massachusetts (US): Jones & Bartlett Learning; 2017.
2. Peter E, Friedland J. Recognizing risk and vulnerability in research ethics: imagining the 'what ifs?' J Empir Res Hum Res Ethics. 2017 Apr; 12(2):107-16.

Elizabeth Peter RN, Ph.D.

*Professor Lawrence S. Bloomberg Faculty of Nursing. Chair, Health Sciences Research Ethics Board. Member, Joint Centre for Bioethics - University of Toronto*