Background

The traditional healthcare student attends school in a sequential manner. They may not have had either the experience of interacting with individuals with chronic health care issues or those who are aware that their disease is degenerative in nature. Effective communication in the healthcare arena, particularly in clinical research requires an understanding of the informed consent process, which by definition requires competence. Loss of competence during a clinical trial, such as can be seen with degenerative diseases such as Parkinson’s disease raises concerns about providing additional protections while preserving respect for persons, beneficence and justice. This project was developed to provide students the opportunity to interact with individuals with different stages of Parkinson’s disease in order to provide real life experiences as a foundation to discuss ethical principles.

Methods

Two patients with Parkinson’s disease gave informed consent to participate in this IRB approved pilot project establish a forum to discuss ethical questions in the context of actual patient experiences regarding clinical trials. The project consisted of 3 phases. Twenty preclinical nursing students were assigned an online tutorial on Parkinson’s disease and were asked to develop questions for the patients who had been invited to the classroom. Faculty members reviewed the questions and grouped them according to themes which were then summarized into a series of low literacy level direct questions. One patient attended each class for a total of 4 classes. Structured debriefing sessions followed each patient encounter. Common themes were identified and discussed.

Results

Three themes related to these encounters consistently emerged:

- Anticipation of direct benefit from clinical trials Limited understanding of concept of research
- Concerns about vulnerability with changing levels of cognition and decision making capacity over the course of a clinical trial (importance of Respect for Persons)
- Desire to contribute to greater good and to make decisions for the future when competency may become impaired

Conclusions

Face to face interactions with patients, each with an awareness of their diminishing capacity had a powerful impact on nursing students. Real life experiences highlighted in patient-classroom discussions provided insight into the ethical issues raised by research participation as well as the importance of additional protections for vulnerable patients. Students felt that they had a greater understanding of the ethical principles outlined in the Belmont Report as a result of this experience. They also felt that this experience brought humanity into the classroom and enriched the curriculum.

“...The patient panel gave me a new perspective on the strength of the human spirit.”

“By speaking to Todd, I know that I should not jump to conclusions based on someone’s physical characteristics or qualities.”

“I cannot thank them enough for sharing their story with our class.”

“Meeting our guest speakers really helped open my eyes to see exactly how difficult it is to adapt.”

“I cannot thank them enough for sharing their story with our class.”

“...Their desire to share their stories and teach future nurses was without a doubt accomplished.”

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