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Whole-Genome Sequencing in the Neonatal Intensive Care Unit (NICU): Nurses' Roles in Communicating Test Results to Families

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Research Process:

The grant I received through the Office of Research and Creative Activities was helpful in supporting this research project. My mentor and I started work on the project early in the year by analyzing the data we had gathered. In 2017, I attended a nursing conference hosted by the National Association of Neonatal Nurses, which is where we surveyed nearly 200 NICU nurses about their understanding of whole-genome sequencing. This survey included both qualitative and quantitative questions. My mentor guided me through the process of interpreting and organizing the qualitative data, which we divided into several subsets within each question.

After my professor and I had reviewed and interpreted the results of our research, we prepared to present our findings at the Western Institute of Nursing conference in Spokane, Washington. Our project was accepted for a podium presentation, so we worked closely together to create a PowerPoint presentation that taught essential background information and clearly communicated the results of our independent research.

Together, my research professor and I traveled to Spokane, Washington, where we worked to memorize and perfect our presentation. We presented our research during a 20-minute time slot to some of the region's most educated nurses, nurse practitioners, and nursing professors. After answering their questions about our project, my mentor and I had a conversation with one of the members of the audience who was a professor of the Neonatal Nurse Practitioner program at another university. We agreed to bring her onto the project in order to have an additional perspective when writing our paper.

The process of writing of the paper began a few months later. My mentor and I met to discuss which research journals we wanted to try to have our paper published in, which would influence the way our paper would read. We also discussed what topics the paper would cover, and which direction we would take it. After this meeting, we separated to work on the different sections: myself on the introduction, her on the body. We met multiple times to reconvene and compare progress on our different sections. We also began meeting with the other professor that we met at the conference. Between the three of us, we re-evaluated the original data and prepared a manuscript to send into our journal of choice.

As a final part of our project, we submitted an abstract to present our research again, this time at BYU's College of Nursing Research conference. This presentation covered much of the same material, this time to an audience of student nurses.

Research Results:

Newborn babies may be admitted to the NICU for a variety of reasons including prematurity, complications of delivery, and genetic disease. As technology improves, practitioners can identify specific genetic diseases more easily. Genetic tests used to be more limited because practitioners would test for a single gene mutation at a time. Recently, with the advent of whole-genome and whole-exome sequencing,

infants with diseases can be diagnosed with specific, rare genetic diseases. In addition to receiving and interpreting information about infants' specific diseases, genomic sequencing has led to a comparison of the benefits and concerns of this new technology.

The purpose of our survey at the National Association of Neonatal Nurses conference was to (1) evaluate the role NICU nurses currently play in educating families of NICU babies who have undergone genetic testing (2) determine how prepared NICU nurses feel to be placed in this role, and (3) evaluate NICU nurses' understanding of potential ethical hazards of disclosing incidental findings to families.

We asked the respondents whether they had treated one or more patients who had undergone genome sequencing. To those that had provided care to one of these patients, we asked how much they talked to the family about the whole genome test results on a scale from zero to five. Sixty-three percent of reported a "zero" for their communication level, meaning they did not talk at all about the whole genome sequence results with the patient families. As a follow-up question, we asked the survey participants to rate their level of preparedness to talk about the test results, on a scale from zero to five. Seventy-three percent of survey participants rated their preparedness at a "zero," meaning that they felt totally unprepared to discuss the significance of the findings.

We asked NICU nurses to write out potential harms and benefits of disclosing incidental findings, and their answers fit within current practice guidelines. They listed emotional distress, unknown significance of findings, and presently unimportant findings as the potential harms of disclosing incidental findings. Potential benefits of disclosing included preparing the patients and families to act preventatively, and that the information may be useful.

We also asked the survey respondents to give rationales for disclosing incidental findings. Their answers could be broken up into five categories: it is the patient's right to know, it causes undo stress, it is important to the patient/health care provider relationship, it is essential to patient and family education, and impacts the future actionability of results.

In conclusion, NICU nurses have a basic understanding of the ethical issues surrounding genomic sequencing, but do not feel fully prepared to discuss results with patients' families. It is important that NICU nurses receive more education regarding this topic, due to the steady increase in genetic testing in NICUs and the role of the nurse as the most present patient and family educator.

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