

2014

Meaningful Ethical Encounters: The Lived Experience of the Genetics Nurse

Elizabeth A. Tinnon

The University of Southern Mississippi, elizabetht1979@gmail.com

Follow this and additional works at: <https://aquila.usm.edu/ojhe>



Part of the [Nursing Commons](#)

Recommended Citation

Tinnon, E. A. (2014). Meaningful Ethical Encounters: The Lived Experience of the Genetics Nurse. *Journal of Health Ethics*, 10(2). <http://dx.doi.org/10.18785/ojhe.1002.04>

This Article is brought to you for free and open access by The Aquila Digital Community. It has been accepted for inclusion in Journal of Health Ethics by an authorized editor of The Aquila Digital Community. For more information, please contact aquilastaff@usm.edu.

Meaningful Ethical Encounters: The Lived Experience of the Genetics Nurse

Cover Page Footnote

Dr. Janie Butts for her encouragement and editing of this work. A heartfelt thanks to the participants of the study, whose voice has now been heard

Meaningful Ethical Encounters: The Lived Experience of the Genetics Nurse

In June of 2000, the first working draft of the entire human genome was completed; healthcare as we know it was drastically changed. Information obtained from the Human Genome Project (HGP, 2011) will provide health care providers with the possibility of improved prevention, detection, and innovative treatments for patients with genetic disorders. These new discoveries are not without risk, but they will be accompanied by new and unique ethical concerns (Henderson, Juengst, King, Kuczynski, & Michie, 2013). Throughout the life span of people across the world, genetic disorders have influenced humanity in a multitude of ways. As a result of this influence and the emergence of new genetic technology, nurses have faced significant moral uncertainty while caring for patients with genetic disorders. Since its beginning, nursing has been a profession concerned with moral perspectives.

Beauchamp and Childress (2013) defined ethics as “a generic term covering several different ways of understanding and examining the moral life” (p. 1). Ethics remains an integral part of nurses caring for patients with genetic disorders (Scanlon & Fibison, 1995; White, 1999; Kirk, 2000; Cassells, Jenkins, Lea, Calzone, & Johnson, 2003; Lea, 2008; Calzone, Jenkins, Prows, & Masny, 2011). Genetics nurses and generalist nurses are observing and managing an expanded scope and depth of ethical concerns in patients with genetic disorders. This broadened scope of nurses’ ethical decision making related to genetic concerns evokes difficult poignant feelings of frustration and sadness because of the permanency of the findings and the implications for generations of people.

Throughout history, nursing has grappled with the ethical implications from scientific discoveries, particularly those involving potential or existing genetic disorders. In a benchmark article, Anderson (1963) indicated that advancing genetic knowledge would come with,

“questions of far-reaching ethical significance” (p. 95). A review of the literature revealed a multitude of ethical issues surrounding the care of the patient with an existing or potential genetic disorder. Issues, such as confidentiality, privacy, autonomy, and issues surrounding genetic testing, competency, and discrimination, have evolved with complexity over time.

Nurses have always recognized confidentiality and privacy as significant ethical issues within nursing. Some patient care involves helping family members face the conflict of managing the permanency and generational implications of the results of genetic disorders (Dugas & Oberleitner, 2009). Kent (2003) recognized that genetic information belongs to the family and not just the individual with a genetic disorder. This notion calls into question the current belief that the patient’s permission is necessary to disclose information. Cassells, Jenkins, Lea, Calzone, and Johnson (2003) conducted a study and found that nurses encountered confidentiality as the most frequent ethical issue in their practice.

However, for all of the issues surrounding the spectrum of genetic testing, and not just nursing practice issues, respect for autonomy is perhaps the greatest concern. As stated in the American Nurses Association’s *Code of Ethics* (2001), nurses have the moral obligation to respect the autonomy of their patients. The principle of respect for autonomy mandates informed consent. The major goal of genetic counseling is to provide patients with necessary information about options for treatment to ensure best patient decision making. Patients with potential genetic disorders may experience undue coercion from close family members to undergo or not undergo genetic testing (Dugas & Oberleitner, 2009).

Informed consent is essential for any patient, but in the case of the patient with potential or existing genetic disorders, Badzek, Henaghan, Turner, and Monsen (2013) emphasized that informed consent has greater significance because the patient must understand all of the risks,

benefits, and implications of the results that have lifelong ramifications. Once genetic results are revealed, they cannot be unknown. Rieger and Pentz (1999) stated that informed consent serves as the foundation for the complete genetic testing process, which means that nursing must enter the international dialogue regarding autonomy and informed consent (Anderson & Rorty, 2001). As the technology continues to grow and new information is uncovered, genetics nurses will have an increased burden of conveying information competently so that patients clearly understand the issues with sufficient scope and depth.

In the 1980s, nurses began to examine the competency of genetic health care providers (Tinley, 1987). This dialogue continued into the late 1990s when Dailey, Pagnotto, Fontana-Britton, and Brewster (1995) examined the role of the genetics counselor and called for additional training to provide quality care in genetics. Jenkins, Diamond, and Steinberg (2001) and Monsen (2009) stated that the greatest concern to nursing was the inadequate preparation of health care professionals to use genetic technology appropriately to provide quality care. Nursing's response to increasing the genetic/genomic competency level was to develop Essential Nursing Competencies and Curricula Guidelines (American Nurses Association, 2009). There is also a call to incorporate genetic/genomic competencies within graduate nursing education (Greco, Tinley, & Seibert, 2012).

The 1990s brought about significant nursing concerns over discrimination based on genetic makeup (Scanlon & Fibison, 1995; Bove, Fry, & MacDonald, 1997). These concerns continued a decade later as Giarelli and Jacobs (2000) pointed out that there is a risk of labeling people according to their genetic makeup, which could lead to oppression, discrimination, and lack of access to health care. Almost another decade later, Williams (2009) reported that not only were healthcare providers concerned about genetic discrimination but also family members.

Congruent with the nursing literature, the Human Genome Project found the following ethical issues and questions surrounding genomic healthcare: (a) who should have access to genetic information?, (b) privacy, (c) confidentiality, (d) how are genetic tests evaluated and regulated for accuracy, reliability and utility?, (e) preparation of genetic health care professionals, (f) difference between medical treatment and enhancement, and (g) commercialization of genetic material (Human Genome Project, 2011).

With the current situation of rapid genetic advancements, nursing must be prepared to deal with the gap between technology and ethical answers to the dilemmas that will be generated by this new knowledge. Nursing literature provides evidence of many ethical concerns of genetics nurses. However, missing in the nursing literature was what meaning the ethical concerns would have for the nurse providing care to the patient with an existing or potential genetic condition.

Methodology

Purpose and Design

The aim of this study was to describe and gain an understanding of the lived experience of genetics nurses as it related to encountered ethical concerns. It was also to inform and improve nursing practice and patient care. A hermeneutic phenomenological approach using van Manen's (1990) methodological themes was the method for this investigation. A hermeneutic phenomenological approach is appropriate because this method addressed the question of what is the meaning of a particular experience. Hermeneutic phenomenology allowed explicated meanings for genetic nurses' experience as human beings living in this world.

Methodological Underpinnings

Munhall's (2012) and van Manen's (1990) methodological perspectives served as the foundation to explore meanings surrounding genetics nurses' experience. Phenomenology is the study of meanings that surround human beings' experiences as they exist in the world and attempts to make known that which is unknown. A basic underlying phenomenological concept is that human beings are a part of the world and do not exist as separate entities from the world. "Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences" (van Manen, 1990, p. 9). Munhall (2012) expressed that idea by stating that phenomenology is "understanding the meaning of being human" (p. 118).

Ethical Considerations

The Human Subjects Protection and Review Committee at The University of Southern Mississippi granted approval for this study. The researcher obtained informed consent, maintained anonymity, and kept the written and recorded transcripts and the researcher's antidotal record in a locked filing cabinet when the writing and rewriting were not in process. Each participant was assigned a pseudonym name for the process and dissemination of the research. The purpose of this phenomenological study was to gain an understanding of the lived experience from the participant's view.

Participants

Purposeful sampling was used to interview participants who had experience with the phenomenon to be studied. The definition of genetics nursing for this study was derived from a discussion on the International Society of Nurses in Genetics (ISONG) listserv, and examination of ISONG's definition of genetic nursing. Based on a modified version of the ISONG's

definition, for purposes of this study genetics nursing is: nursing that focuses on providing care to patients and their families, who have known genetic conditions and/or birth defects, or who are at risk to develop them. The definition of nursing care encompassed the role of the direct care provider, the academic nurse educator, and the researcher. To ensure that the participants were knowledgeable regarding the phenomenon, other criteria included: (a) 2 years or more of genetics nursing practice, (b) at least 12 months of the practice time in the clinical setting, and (c) 75% of their professional role was providing genetics care to patients and their families.

During the discussion on the ISONG listserv regarding the definition of genetics nursing, several ISONG members expressed an interest in participating in the study; they were contacted and asked to participate. The participants ranged from 3 years to 20 years of experience in caring for patients with existing or potential genetic disorders. There was also a variety of clinical areas noted among the participants including oncology, cardiology, neurology, family practice, and pediatrics. At the conclusion of six interviews, saturation had been achieved, but the researcher conducted two more interviews to ensure richness of the data. A request was posted on the ISONG listserv, and the first two respondents who met the criteria were included in the study.

Data Collection

Eight genetics nurses participated in the study and provided information on nurses lived experience as it related to ethical concerns. Five face-to-face interviews and three phone interviews were conducted. The interviews lasted from 1 to 2 hours. Settings for interviews were held in naturalistic places, varied for participants, and conducted at a place and time that was convenient for participants.

The interview process began with an inquiry of the genetics nurses' job description and experience:

1. Please describe for me what you do as a genetics nurse.
2. What is it like to be a genetics nurse and to encounter ethical issues regarding patients and families with genetic disorders?
3. Can you give me an example of an ethical concern that would crystallize, for you, what we have been discussing?

The remainder of the interview followed a natural discourse with the researcher encouraging full descriptions and clarification.

Data Analysis

Each interview was recorded, and a verbatim transcript was created from recorded interview. Data analysis began with the first interview; the researcher began to examine the phenomena as the participant began to answer questions. After the transcription of the interviews, the researcher began to examine the text for significant words related to the phenomenon. Turning to the phenomenon consisted of orienting to the phenomenon, formulating the phenomenological question, and explicating assumptions and pre-understandings. Orienting to the phenomenon was to approach the phenomenon with a deep interest (van Manen 2009).

Orientation required that the researcher interact with the text, beyond simply reading what is written. One must become immersed and intimate with the text. As part of the hermeneutic phenomenological reflection process and using van Manen's (2009) selective or highlighting approach, the thematic analysis began. Meaning can only be conveyed through language, both written and or spoken.

The texts were examined repeatedly for essential statements that revealed the phenomenon, then the text was highlighted. For example, confidentiality was a term used often by the participants. Once confidentiality was established as a theme, the researcher began to look for evidence of this throughout the narratives and color coded all the text that revealed phrases that addressed aspects of confidentiality. Using van Manen's (2009) composing linguistic transformation process, the researcher isolated thematic statements and then transformed the texts in phenomenologically sensitive paragraphs. Individual and group thematic analysis conducted by the researcher will be presented in the findings. The final step in hermeneutic phenomenological reflection was separating the essential themes from the incidental.

Methodological rigor.

Methodological rigor included the use of (a) truth value, (b) applicability, (c) consistency, and (d) neutrality (Munhall, 2012; Sandelowski, 1986; 1993). The research illustrated faithful descriptions of the participant's narratives. Truth value was assured with member checking and prolonged time spent with participants and subsequent narrative. Comments from the participants included, "You got it, you really understand," and "I wouldn't change a thing; I have never heard what I do put so correctly and concisely." Applicability was evident as the researcher gave each participant's narrative equal weight and presented the data that were not similar in nature. To ensure consistency, the researcher maintained a notebook, which included anecdotal notes, memos, and written descriptions of the researcher's emotions and observations recorded during the research process. Neutrality was maintained throughout. At the beginning of the study the author explicated known biases and assumptions so as not to influence or confuse the findings with the author's experiences.

Findings

It is within the participant's own words that researchers are able to begin to capture the meanings surrounding and embedded within the practice and experience of genetics nursing. Seven essential themes emerged from the narratives: (a) caring over time, (b) shared pain and suffering, (c) my job is to educate, empower, and equip, (d) not my decision, (e) fight for the patient, (f) anger surrounding misinformation, and (g) the complexity and conflicts of maintaining confidentiality.

Caring over time

Interwoven into the nurse-patient relationship was an experience in temporality. Genetics nurses experienced temporality as caring over time because they cared for patients whose disorders would span a lifetime.

Nurses always care a lot about their patients. You care about your patients when you work in the emergency department, but most of them are in and out of your life in a relatively short period of time, but my patients aren't. They'll have to see and be examined every six months. So that's different. You don't think about that...but that's this person will never be detached from my...from the medical field or us, you know, for the rest of their life.

The participants also shared the positive and negative aspects of caring for patients over long periods of time.

Positive: Just, you know, by virtue of longevity and involvement that's a really positive aspect of my practice.

Negative: *It can be painful, painful aspect when something really bad happens or a patient dies, for instance, that you have been taking care of for a number of years.*

Shared pain and suffering

Participants detailed their experience of shared pain and suffering. Once participants observed pain and suffering of the patient and family, this also became their own experience. Pain and suffering were an experience of the body being in this world. Shared pain and suffering was experienced at the physical and emotional level.

You have a heavy heart when you walk away; you just have this weight on your heart.
I feel sorrow, you know because something, something bad is happening and something...you rarely resolve these without pain and suffering. If the mother says yes and the father says no, somebody is going to be hurt; you don't have these kinds of situations without somebody suffering, and you know you're empathetic you're suffering, you know you see people suffering, you're suffering along with them.

Pain was more intensified for the genetic nurse if the resulting positive test was for a disorder with no cure.

That's really the hardest part is watching people make that kind of decision and then finding out the test is positive and they do have it and there's no cure. There is nothing we can do about it.

The participants shared that pain and suffering could be costly in terms of the emotional toll on them during the process of care. They shared how the repetitiveness of genetic counseling increases the pain.

I mean, I feel like giving and giving and giving and talking about this, and taking in all of this grief with these people as a nurse. It is very hard on you to go through that time after time after time.

My job is to educate, empower and equip

The participants revealed that providing information in the decision making process was a crucial piece of genetics nursing as it related to ethical concerns. Although always important to nursing, patient education takes on a different, more specialized meaning when it is related to genetic disorders. Because it is likely that decisions made by one person will have far reaching ramifications for the entire family, patients need to understand the risks, benefits, and consequences of their choices.

You know, to be able to know that I have done to the best of my ability, my job, as far as laying out the information. Without understanding the patient can't make an informed decision. And I just don't think that they have...they really understand exactly what they're doing...shared how she often must translate and interpret what the physician has said to the patient. So you um you know I can spend a lot of time with patients and that's why I really love doing this job because I can bring the knowledge down to their level so that they really understand what's going on.

Information became paramount when the family began to realize that future pregnancies could have enormous risks.

We just need to kind of equip them with everything that they need to take care of themselves because they are their own best advocates in the long run. Once we have one affected child, you know, we always make so sure, that we explain the inheritance

to the families. We try to just tell it to them every way we can to make them understand what they are at risk for.

The genetics nurses' believed knowledge would drive away the patient's fear, reduce their anxiety, and assist them in the journey of decision making.

You know really wanting to help her not be so fearful, help her get the information she needed, help her make the decision that's gonna work for her. I think these women need someone to talk to who can give them good information and who is willing to listen in a way that helps them get to where they need to be.

The genetics nurses revealed a fear of failing if patients did not "feel better" following patient education.

And my whole thing was, if they're more anxious when I'm done with them than when they came in, then I have done a bad job. Because that means that I haven't addressed their fears. I just believe the whole process of empowerment and the whole process of knowledge is to drive down fear.

That I could make it better; I could make it, you know, a little less scary, a little more empowering.

Once correct information is given, the patient has an option to ignore the information or respond to the information. Participants could not understand the reasons that their patients would chose *not* to know.

It's really strange for me because I want to know, knowledge is power in everything. I think...relieved sometimes because the enemy that you know is better than the enemy that you don't know and it's an answer.

Not my decision to make

Participants repeatedly indicated that patient autonomy was the overriding ethical principal. Participants distinguished different roles within the decision making process. The predominant role of the genetics nurse was to provide information to the patient to increase an understanding of the circumstances, and the role of the patient was to make an autonomous, informed decision. The participants also believed that having a non-judgmental attitude regarding the patient's decision was essential to protect patient autonomy. Another essential aspect was for genetics nurses to give correct information. Participants believed that their accountability and responsibility begin and end with providing information for autonomous patient decision making.

My role is to provide the information; their role is to make the decision.

It's like, okay, I mean I can't, I can't force, and I won't force, anybody to do anything. So you can encourage them. You can educate people, but you cannot make them do anything that they don't want to do.

The participants believed that influencing the patient with their own biases was not acceptable because patients would know what was in their own best interest. The ability to separate themselves emotionally from the decision was enhanced by maturity and experience and was closely tied to the participants' belief that their responsibility ended with providing information.

I used to feel bad if people didn't do what I thought was the right thing for them to do, or they didn't do what I thought the doctor wanted them to do, and then I would feel bad about that. I've gotten a lot better with being, I feel, being a little bit more objective and just presenting the information and recognizing that, there are

differences in how people view things and there are differences in how they want to work within them.

Fight for the patient

Each of the participants indicated “fighting” for their patients. The participants’ narratives revealed fighting other health care professionals, government bureaucracy, insurance companies, ignorance, and judgmentalism. Battling for the rights of the patient became a focus—the right to treatment and insurance, and the right to make a decision that involved loss and death. Genetics nurses engaged in battle on a daily basis because they were yelled at and humiliated by other health care professionals. The participants described several tools to use in fighting for the patient. Tools included writing letters to insurance companies, faxing information back and forth, making endless phone calls, and having a physical presence.

I guess the battles have primarily been with letters, letters to insurance companies to write back to them and say this is why this needs to be , and then write back to them again, this is why it needs to be. You know it’s really hard when you know what needs to be done and you just can’t make the system work right. I am not willing just to sit back and watch this happen to people. It’s very, very I can’t tell you how gratifying that it is to know that I had a part in that, to be able to prevent someone from dying.

I just try to help them do whatever it is they can do to get treated for whatever they have, I guess the bottom line is, I just do what it takes.

Anger surrounding misinformation

The participants shared narratives of caring for patients who had been referred to that setting and had no idea that they were being testing for a potential genetic disorder. One of the more poignant narratives was when a patient was tested for Huntington's Disease but had never been counseled regarding the disease or implications of the results.

I'd ask them do you know that your doctors have referred you to genetics for an appointment and they would say no, like they are completely shocked and amazed. I think there is a lot if misinformation out there and I think that sometimes the ethical issues that pop up may be precipitated, you know, by that misinformation.

Some of the participants expressed anger at other healthcare providers for not properly counseling patients on risks, benefits, or potential outcomes prior to genetic testing. The majority of the participants believed that misinformation began with the healthcare provider's knowledge deficit related to genetics, and that this misinformation could harm a patient.

No, I don't know what to say except that when you do lose some because of it, I don't think negligence was the word, but because of ignorance.

It aggravates me that other healthcare professionals are ordering genetic testing without either themselves having all the information they need to have or giving the patient or the family all the information they need. People ought to be able to know exactly what they're being tested for and what the likelihood is that they're gonna get an answer and what that answers gonna mean to them as an individual or to their family before they give consent to be tested. You may feel anger at other healthcare professionals. You know when you find somebody is x number of years old and has a

particular disorder, and you know something could have been done if somebody would have referred them 5 years ago. That's not a happy feeling.

The complexity and conflicts of maintaining confidentiality

Maintaining confidentiality of the patient was integral to genetics nurses' experience with ethical concerns, which consisted of internal and external conflicts. Medical information in general was regarded as confidential, but genetic information was regarded as even more sensitive to confidentiality because of the permanency of the results and the generational implications. Maintaining confidentiality was more than just following a law, or ethical principle. Participants revealed they protected this information tenaciously from other health care providers, friends, and even intimate family members.

I will not give anybody's results except to that patient, and so don't ask me to violate that

There was a lot of stuff with her case because, because she didn't want to tell anybody at work what was going on. So when I called her, I had to say her first name and I could not say who I was or where I was calling from. She was very secretive about her appointments.

I tell them "I can't tell your mother, I can't tell your father, I can't tell your brothers, or sisters or your children. I am very clear with this up front.

Maintaining privacy and confidentiality when there were multiple families and generations involved could become complex and fraught with increasing stress levels and frustration. Participants expressed that genetics nurses accidentally find themselves aware of confidential information that causes internal conflicts.

A few participants cared for several close family members at the same time and discovered that each family member had a different response to privacy and confidentiality regarding the results of genetic testing. Genetics nurses are responsible for supporting each of the family members in their choice. They discovered themselves protecting the information from close family members, even in the midst of conflict. Participants related times of anger and frustration with patients who refused to share crucial genetic information with other family members because of previous conflicts within the family.

I've had cousins and other family members that they don't talk to anymore, you know I have really had to work with these people but you can't force them to tell the cousins. I would feel like that person would benefit and it would be in that person's best interest and that person might have better health, then I would feel conflicted, might feel frustrated and even a little bit of anger.

Sometimes participants expressed a great burden of pain regarding the nature of confidential information because within that confidential information exists a patient who chooses to keep that information hidden. One of the participants expressed that her greatest pain in genetics nursing was carrying the knowledge of someone's deepest secret.

Their mother has never been able to look me in the eye since she made that decision to terminate the pregnancy. And, I just, you know, every time I see her, I just feel like I'm a reminder of something, you know, a horrible part of her life. And I, that's definitely the situation that has caused me the greatest pain. If it was just affecting me then that's my issue and I can deal with that. But I know it's affecting her. I know it was making her very uncomfortable just by my presence and I can't do anything to make that better for her.

Maintaining patient confidentiality was a complex endeavor with many ethical concerns to consider. Genetics nurses' relationships with patients could become extremely stressful when decisions of confidentiality conflicted among the different family members. One of the participants shared a narrative about a mother and daughter in conflict regarding genetic testing. A mother who was at risk for a genetic disorder did not want to know her genetic status; however her adult daughter wanted to know her own genetic status. The daughter approached the participant with the request for genetic testing and promised not to inform her mother of the results.

I ultimately decided she had the right to be tested, but was very uncomfortable with proceeding on that basis. The daughter did tell the mother that she was pursuing genetic testing, and the mother confronted me and was very upset. I felt betrayed by the daughter, and was very frustrated by the whole process, but it was, you know, that's definitely an ethical issue because whose rights have the precedence?

Discussion of Findings

Relationship was the underlying pattern of this study. The significance of relationship was uncovered in the narratives of each participant's experience. Nursing in general is a relational endeavor; however, because of the long-term care required for the patient with genetic disorders, genetics nurses develop a unique relationship with their patients. In that relationship are positive and negative aspects. The participants enjoyed sharing in the positive life experiences; other times they grieved when they lost a patient. Participants discovered they sometimes experienced a negative emotional toll because of the repetitive nature in the provision of care to their patients. Ford and Turner (2001) conducted a hermeneutic phenomenological study of 4 pediatric nurses who cared for hospitalized children with special needs and their families. They reported that the

nurses in the study developed unique relationships with their patients. The nurses stated that they developed special relationships with the patients with special needs, reporting an increased level of involvement and investment, more so than usual. They also found that the relationships could take an emotional toll with the level of investment in the relationship.

Participants believed that distinct roles existed in the informed consent and decision making process. The participants were adamant that a predominant role of genetics nurses was to equip the patient with the necessary information for making an informed decision as it was the patient's decision to make. Cignacco (2002) conducted a qualitative inductive study with a sample of 20 midwives who assisted in selective termination of pregnancy when there was a pathological condition of the fetus. Cignacco found that midwives, like the participants, believed strongly in autonomy and self-determination of the patient. Both the genetics nurses and the midwives reported a personal conflict between their own value system and the decision made by the patient. The participants in the current study expressed that shared pain and suffering occurred as they observed the patients making decisions or living with the results of decisions made.

Regardless of the ultimate decision, participants believed it was their moral responsibility to support the patient, even when they personally disagreed with the decision. At times, the patient's right not to know and their refusal to share significant information with other family members caused the participants to experience significant emotional distress.

It was obvious through the participant's narratives that caring simultaneously for multiple family members with the same genetic disorder created some of the greatest perplexing ethical dilemmas. Participants revealed an increased tension when caring for multiple family members simultaneously. This tension will only increase as genetic technology advances and subsequent ethical dilemmas become more complicated (Conley, Biesecker, Gonsalves, Merkle, Kirk, &

Aouizerat, 2013). Some authors have suggested ethical frameworks to help guide nurses through ethical dilemmas specific to genetic/genomic care. Two suggested examples include the American Nurses Association's *Code of Ethics* (2001; Dugas, 2005) and the Ethical Assessment Framework, (Cassells, Jenkins, Lea, Calzone, & Johnson, 2003). While genetics nurses might find these frameworks helpful in approaching ethical dilemmas related to care of the genetic patient, they are not specific to managing conflicting rights within families.

Doukas (2001) suggested a covenant model to assist health care providers, patients, and their families in decision making. His model included the family in decision making as opposed to the traditional medical model of one patient, one physician. Quillin and Lyckholm (2006-2007) presented a principle based approach to predictive genetic testing for breast cancer. Their framework was based on the principles of primacy of the patient, patient autonomy, social justice, beneficence, and non-maleficence. This approach allows for an examination of some of the intricacies in caring for multiple family members, but does not facilitate analysis of all of these intricacies.

It is difficult to convey in writing the depths of emotions, primarily anger and frustration that were expressed by the participants regarding misinformation and improper genetic counseling. This particular topic evoked the most intense feelings because of the possible patient consequences due to incompetent or uninformed health care providers. This, according to the participants, could cause unnecessary testing, and improper counseling, which ultimately could prove to be fatal for the patient. Despite the earlier call for increased genetic/genomic information within the curriculum of healthcare disciplines (Cohen, 1979; Monsen, 1984; Jenkins, Dimond & Steinberg 2001), there are more recent studies which indicate nursing has not achieved the educational level and competency of health care providers necessary to provide

appropriate care. (Badzek, Turner, & Jenkins, 2008; Calzone & Jenkins (2011), Maradieque, Edwards & Seibert, 2013). Every nurse is not expected to have advanced training in genetics according to the American Nurses Association (2008), but generalist nurses should be able to (a) perform a physical assessment on all patients and recognize any findings that might indicate genetic implications, (b) construct a pedigree, and (c) provide referrals for further genetics care.

Validation of the study's other ethical concerns is confirmed in numerous articles related to genetics (Erlin, 2006; Wicken, 2011). Lea (2008) also noted some of the same ethical issues that were found in the current study: (a) informed decision making, (b) informed consent and genetic test, (c) maintaining privacy and confidentiality of genetic information, (d) preventing genetic discrimination, (e) strengthening genetic and genomic care around the world, and (f) nursing competencies for ethical issues in genetic and genomic healthcare.

While the focus of the study was nurses caring for patients with genetic disorders or potential disorders, the findings are important for the generalist nurse as well. As genetic/genomic discoveries and technology increase, generalist nurses will find themselves caring for more patients with genetic disorders or patients with diseases that have a genetic component. The findings of this study will provide generalist nurses a beginning point for understanding the meaning and process of caring for patients with genetic disorders or potential genetic disorders.

Limitations

The small sample size, while appropriate for a hermeneutic phenomenological study, limits the generalizability of the study. In examining the research questions and reflecting on the narrative and research design, research question one may not have been posed from an entirely phenomenological perspective; however, it did give the researcher the background in which to

place the context of the study. Despite this limitation the participant's narratives did explicate the lived experience of the genetics nurse. As some of the participants expressed interest in participating during the initial conversation to define genetics nursing, this study may include some bias.

Conclusions

This study gave the participants a voice to validate and explicate their experiences of caring for patients with genetic or potential genetic disorders. Caring for these patients does create unique ethical concerns with significant meaning for genetics nurses. How then, do we translate these findings to support genetics nurses and the generalist nurse in traversing the ethical landscape of caring for patients with genetic disorders or potential genetic disorders?

Continued diligence integrating genetic/genomic information into the nursing curriculum is necessary. It is not just the physiological content and disease processes that should be included but also ethical concerns associated with care for patients with genetic disorders or potential genetic disorders. As the number of patients with genetic disorders or potential genetic disorders expands and the shortage of nurses, particularly genetics nurses, continues the generalist nurse will assume an increased responsibility for basic genetic assessment and appropriate referrals.

Recommendations for further study include an in-depth examination of the ethical intricacies arising from caring for multiple family members with the same genetic disorder during the same time interval. While there have been some suggested frameworks, nurses might explore new models of patient care that address family dynamics related to the consequence of increased capacity for genetic testing.

Nursing needs to further examine the depth and intensity of emotional distress experienced by the genetics nurse. Ways to support the genetics nurse should be explored and developed.

As ethical concerns related to genetics are better understood, genetics nurses will better illuminate what values and beliefs they bring to their own ethical decision making process and to their role in assisting patients through ethical deliberation. The ethical knowledge and meaning gained from this research will benefit all nurses

References

American Nurses Association, (2001) *Code of ethics for nurses with interpretive statements*

Silver Spring, MD: American Nurses Association.

Anderson, G. & Rorty, M. V. (2001). Key Points for Developing an International

Declaration on Nursing, Human Rights, Human Genetics and Public Health Policy.

Nursing Ethics 8 (3):259-271.

Anderson, R. (1963). From peas to people. *Nursing Science*, 1, 94-104.

Badzek, B., Henaghann, M., Turner, M., Monsen, R. (2013). Ethical, legal and social issues in the translation of genomics into healthcare. *Journal of Nursing Scholarship*, 45(1), 15-24.

Badzek, B., Turner, M. & Jenkins, J. (2008). Genomics and nursing practice: Advancing the nursing profession. *The Online Journal of Issues in Nursing*, 13(1). Retrieved from <http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/vol132008/No1Jan08/GenomicsandAdvancingNursing.html>

Beauchamp, T. & Childress, J. (2013) *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

Bove, C., Fry, S. & MacDonald, D. (1997). Presymptomatic and predisposition genetic testing: Ethical and social considerations. *Seminars in Oncology Nursing*, 13(2), 135-140.

Calzone, K. & Jenkins, J. (2011). Genomic education in nursing in the United States.[Special issue]. *Annual Review of Nursing Research*, 29, 151-172.

Calzone, K., Jenkins, J., Prows, C., & Mansy, A. (2011) Establishing the outcome indicators for the essential nursing competencies and curricula guides for genetics and genomics. *Journal of Professional Nursing*, 27(3), 179-191,

Cassells, J., Jenkins, J., Lea, D., Calzone, K., & Johnson, E. (2003). An ethical assessment framework for addressing genetic issues in clinical practice. *Oncology Nursing Forum*, 30(3), 383-390.

Cignacco, E. (2002). Between professional duty and ethical confusion: Midwives and selective termination of pregnancy. *Nursing Ethics*, 9(2), 179-191.

Cohen, F. (1979). Genetic knowledge possessed by American nurses and nursing students. *Journal of Advanced Nursing*, 4, 493-501.

Conley, Y., Biesecker, L., Gonsalves, S., Merkle, C., Kirk, M. & Aouizerat, B. (2013). Current and emerging technology approaches in genomics. *Journal of Nursing Scholarship*, 45(1), 5-14.

Consensus Panel Genetic/Genomic Nursing Competencies. (2009) *Essential of genetic and genomic nursing: Competencies, curricula guidelines and outcome indicators* (2nd ed.). Silver Spring, MD: American Nurses Association.

Dailey, J., Pagnotto, M., Fontana-Bitton, S., & Brewster, S. (1995). Role of the genetic counselor: An overview. *Journal of Perinatal Neonatal Nursing*, 9(3), 32-24.

Doukas, D. (2001). The family covenant and genetic testing. *American Journal of Bioethics*, 1(3), 2-10.

Dugas, J. & Oberleitner, M. (2009). Redefining the conventions of informed consent:

Challenges in the genomic area. In: Rita M (ed) *Genetics and ethics in health care*. Silver Spring, MD: American Nurses Association.

Dugas, R. (2005). Nursing and genetics: Applying the American Nurses Association's code of ethics. *Journal of Professional Nursing*, 21(2), 103-113.

Erlin, J. (2006). Genetic testing and counseling: Selected ethical issues. *Orthopaedic Nursing*, 25(6), 423-426.

Ford, K. & Turner, D. (2001). Stories seldom told: Pediatric nurses' experiences of caring for hospitalized children with special needs and their families. *Journal of Advanced Nursing*, 33(3), 288-295.

Giarelli, E. & Jacobs, L. (2000). Issues related to the use of genetic material and information. *Oncology Nursing Forum*, 27(3), 459-467.

Greco, K., Tinley, S. & Seibert, D. (2012). *Essential genetic and genomic competencies for nurses with graduate degrees*. Silver Spring, MD: American Nurses Association and International society of Nurses in Genetics.

Henderson, G., Juengst, E., King N., Kuczynski, K., Michie, M. (2012). What research ethics should learn from genomic and society research: Lessons from the ELSI congress of 2011 *Journal of Law, Medicine & Ethics*, winter, 1008-1024.

Human Genome Project. (2011). Medicine and the new genetics,

http://www.ornl.gov/sci/techresources/Human_Genome/medicine/medicine.shtml,

accessed May 2011).

Jenkins, J., Diamond, E. & Steinberg, S. (2001). Preparing for the future through genetics nursing education. *Journal of Nursing Scholarship*, 33(2), 191-195.

Kent, A. (2003). Consent and confidentiality in genetics: Whose information is it anyway?

Journal of Medical Ethics, 29(1), 16-19.

Kirk, M. (2000). Genetics, ethics and education: Considering the issues for nurses and midwives. *Nursing Ethics*, 7(3), 215-225.

Lea, D. (2008). Genetic and genomic healthcare: Ethical issues of importance to nurses. *Online Journal Issues in Nursing*, 13(1), 1-14.

Maradiegue, A., Edwards, Q. & Seibert, D. (2013). 5-years later: Have faculty integrated medical genetics into the nurse practitioner curriculum? *International Journal of Nursing Education Scholarship*, 10(1), 245-254.

Monsen, R. (1984). Genetics in basic nursing program curricula: A national survey. *Maternal Child Nursing Journal*, 4, 177-185.

Monsen, R. (2009). Genetics and ethics in nursing: New questions in the age of genomic health. In: Rita M (Ed.), *Genetics and ethics in health care*. Silver Spring, MD: American Nurses Association.

Munhall, P. (2012) *Nursing research: A qualitative perspective* (5th ed.). Sudbury, MA: Jones & Bartlett.

National Human Genome Research Institute. (2011) ELSI research priorities and possible research topics, <http://www.genome.gov/27543732> (accessed May 2011).

Quillin, J. & Lyckholm, L. (2006-2007). A principle-based approach to ethical issues in a predictive genetic testing for breast cancer. *Breast Disease*, 27, 137-148.

Rieger, P. & Pentz, R. (199). Genetic testing and informed consent. *Seminars in Oncology Nursing*, 15(2), 104-115.

Sandelowski, M. (1993) Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16(2), 1-8.

- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27-37.
- Scanlon, C. & Fibison, W. (1995). *Managing genetic information: Implications for nursing practice*. Washington, DC: American Nurses Publishing.
- Tinley, S. (1987). Nurses' and geneticists' role expectations for the genetics nurse clinician. *Journal of Pediatric Nursing* 1987, 29(4), 259-264.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive Pedagogy*. Ontario, Canada: State University of New York Press.
- White, M. (1999). Making responsible decisions: An interpretive ethic for genetic decisionmaking. *Hastings Center Report*, 29(1), 14-21.
- Wilcken, B. (2011). Ethical issues in genetics. *Journal of Paediatrics and Child Health*, 47, 668-671.
- Williams, J. (2009). Concerns of patients and families surrounding genetic testing. In: Rita M (Ed.), *Genetics and ethics in health care*. Silver Spring, MD: American Nurses Association.