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Parental Knowledge and Misconceptions of Risks to Healthy Newborns in Genotypic Driven Pediatric Research

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Abstract

Purpose: To describe parental knowledge and misconceptions of genetics.

Study design and methods: A qualitative, descriptive study utilizing semi-structured interviews (n=32) was conducted in private rooms with mothers or mother-father dyads 24-48 hours after the birth of their healthy, full-term infant. Audio recording and field notes were collected. Thematic analysis identified major categories pertaining to parental knowledge of genetics in healthcare.

Results: Two themes were identified: parental lack of knowledge and misconceptions of genetics in healthcare and parent's perception of the value of the genetics in healthcare. Parental source of genetic information emerged as an accounting of where parents obtained genetic information. Thirty-eight percent of parents felt they had little knowledge of genetics. Twenty percent of parents acquired their genetic information from personal experience. Seventeen percent of parents acquired their genetic information from public media, and 10% of parents acquired their genetic information from someone who experienced genetic testing. Parents perceived value in prenatal diagnosis of variable conditions or disease but had mixed opinions on the value of genetics in healthcare after the child was born.

Clinical implications: Significant gaps and misunderstandings in parental knowledge of genetics were identified. Removing potential parental knowledge barriers is essential for parental understanding of the role of genetics in health, illness, and pediatric genetic research.

Keywords: Infant; Pediatric; Genetics; Parents

Introduction

Genetic risk assessments for children and adults are developed from family histories, clinical assessments, genetic testing, or any combination of the three. Unlike parents of infants who are identified prenatally as at-risk or potential carriers of genetic conditions, parents of healthy or unaffected newborns feel uninformed and unprepared for genetic information presented to them [1]. This disparity in parental genetic knowledge is a significant concern because clear and evidence-based information is necessary for parents to understand the role of genetics in newborn healthcare and appreciate the range of medial opportunities available to them [2]. This article will describe parent's knowledge of genetics and their perceptions of genetics in healthcare.

As the origins and evolution of genetic disease become more evident, the public is increasingly faced with the charge of considering their genetic risk of disease [3]. Genetics plays a significant role in health and public policy, yet recent studies of the general public's genetic literacy show a relatively low understanding of genetic concepts [4]. Personal perceptions of genetic disease risk influence an individual's decisions about prophylactic surgical interventions (such as mastectomy [5], oophorectomy [6] and colectomy [7]) and the belief in the effectiveness of medication [8]. In pediatrics, genetic risk assessment is further complicated by the fact that parents must make health care decisions based on their understanding of their child's genetic risk. Without a basic knowledge of genetics, parents may find it difficult to make informed decisions about the health of their child.

Failure to understand treatment options derived from genetic research may adversely affect the health of their child. Genomics plays a role in 9 of the 10 leading causes of death, including: heart disease, cancer, stroke diabetes and Alzheimer's disease. For people who are at increased risk for hereditary breast and ovarian or hereditary colorectal cancer, genetic tests may reduce their risk by guiding evidence-based interventions [9,10]. Genetics and genomics have the potential to improve health in a variety of ways by informing about disease diagnosis, prognosis, risk, prediction, prevention, and treatment, including medication choice and dosage [11].

For some time now, genetic research has been conducted on infants, who are at-risk or potential carriers of genetic conditions [12,13]. The justification for the donation of DNA from these at-risk infants has been that the medical benefits to the infant outweigh the potential risks [14]. Healthy controls in pediatric genetic research are essential for determining valid study results. However, acquiring DNA for research from healthy infants is more difficult than acquiring DNA from at-risk infants [15]. The National Children's Study, closed in December 12, 2014 due in part to low recruitment [16], determined that obtaining DNA from healthy infants was more problematic than obtaining DNA from at-risk infants due in part to parental knowledge deficit, attitudes and concerns about genetics and the risks for their healthy infant [17].

Very little is known about public knowledge and attitudes of genetics and genetic testing [18]. Three hundred adults from a south-east state were recruited to assess health literacy, genetic knowledge, and attitudes towards genetic tests. The sample included primarily higher

income (≥ $60K), well educated (BS or higher –70%), young (age 18-29 - 44%), white (60%), females (70%) with a family history of type II diabetes mellitus (T2DM) (70%). Given that the percentage of general population with T2DM family history is less than half (approximately 30%) than those who responded and were recruited, concern for their risk may have influenced participation. Using validated instruments, they found no difference in genetic knowledge among those with and without genetic risk. However, direct to consumer marketing of genetic testing indicated that services are sought by persons who perceive they have a risk [19]. Participants in the study by Haga et al. had a positive attitude towards genetic testing and expressed knowledge of disease-related concepts consistent with published facts, yet less than half were aware of existing federal legislation protecting them from insurers or employers adversely using findings of genetic tests. The authors conclude that to ensure informed decisions, we should provide more information about the risk, benefits, and limitations of genetic testing such that decision making is informed "both in the context of health care and in terms of one's overall sense of personal well-being and social identify" [18].

Genetic risk assessment of healthy children is more problematic. At risk mothers and mothers with breast cancer believe that having genetic information about breast cancer mutations may lead to a cure, improved surveillance or screening [20]. But in a separate BRCA surveillance program, only 18 of 104 parents would test their own healthy child although 25% of parents agreed to the testing as policy [21]. In a more recent study, 219 parents were offered the opportunity to have their child participate in a multiplex genetic test for susceptibility to 8 common, adult-onset health conditions. Parents were only moderately interested in pediatric testing. Valuing gene-health knowledge was a significant factor [22].

Universal newborn screening (NBS) began in 1963 and is required by every state for a variety of disorders such as inborn errors in metabolism, endocrine disorders, congenital heart disorders, cystic fibrosis, and hearing loss. Over 12,000 children are identified each year and benefit from early identification and treatments. The number of disorders screened for continues to increase with some states now screening for up to 52 disorders [23].

In addition to the state prescribed panel, NBS may uncover incidental findings such as carrier status, secondary targets such as non-sickle-cell hemoglobinopathies, and borderline results such as non-classic cystic fibrosis and mild forms of targeted disorders [24]. Some screening findings are predictive, not diagnostic, and findings may be false positive, requiring a confirmatory test. Screening is also taking on a life-course perspective and screening beyond childhood onset disorders. The American College of Obstetricians and Gynecologists provides several informative resources for healthcare providers, and includes links to online brochures that may be printed and used to educate parents [25]. Computer aided interactive information on genetic testing has been suggested as a means of distributing information tailored and adaptable to both low and high literacy populations [26].

The paucity of literature on parental knowledge of pediatric genetics has focused on genetic testing and the at-risk infant and their family. There is little information about parental genetic knowledge with healthy, asymptomatic, or presymptomatic infants. The purpose of this article is to fill a gap in the nursing literature by describing the genetic knowledge and misconceptions in healthcare of parents of healthy infants. This study answers the following qualitative research questions: What knowledge or parental perceptions influence parent's perspectives about genetics in healthcare? Do parents of healthy newborn infants perceive pediatric genetics as valuable or an important achievement in medicine? Where do parents get their information about genetics?

Study Design and Methods

Study design

A qualitative descriptive approach [27] was used to describe parental knowledge and perceptions of pediatric genetics. The institution's Institutional Review Board approved the study. Semi-structured interviews were conducted with parents involved in a concurrent mixed methods study [28]. The purpose of the mixed methods study was to explore the process and factors that influence parent's decision to donate their healthy infant's DNA for minimal risk genetic research. The parent study answered the following qualitative research questions: What are the process parents utilized to arrive at a decision to enroll their healthy infant in minimal risk genetic research? What do parents of newborn infants perceive as factors that influence their decision to donate their healthy infant's DNA for minimal risk genetic research?

Setting

All participants were recruited from an urban teaching hospital postpartum unit with 5,000 births annually. The hospital is located in a major US Northeastern city. The interviews took place in the mother's private rooms.

Sampling methods

This qualitative descriptive study was part of a concurrent mixed methods study (QUAL + QUAN) with a convenience sample of postpartum mothers and mother-father dyads (n=32). Only parents participated in the study. Infants were not enrolled in the study. Purposeful sampling identified parents who met the eligibility criteria. Eligible parents were fluent in English, had delivered a full term infant (gestational age greater than 37 weeks of age), the infant had not been admitted to the neonatal intensive care or intermediate care nursery, and did not present with an acute or chronic illness (e.g. respiratory distress, unable to maintain temperature, feeding difficulties etc). All parental interviews were conducted 24 - 48 hours after delivery.

Semi-structured interview guide

Interviews for this study utilized the same methodology as the parent study [28]. Semi-structured interviews were utilized for all qualitative interviews. Interviews were conducted using a funneling technique that began with demographic questions, evolved towards general questions about genetics [29]. The structure of the probing questions mirrored the structure of the interview. Probing questions progressed from open ended general questions to specific questions about genetics. Interviews described and clarified parental ideas. All mother or mother-father dyad questions maintained the same focal area to ensure dependability in data [30].

This analysis describes parental response to specific question about parental knowledge of pediatric genetics not explored in the parent study. Parents were asked general questions about their knowledge of genetics, "What do you know about genetics?" If parents stated they had undergone genetic testing or they know someone who had undergone genetic testing, parents were asked probing questions such as: What was the test? What were the circumstances? How did they/you make the decision to be tested? How did they/you feel about it? As the interview progressed, questions moved towards specific questions "Do you think there is the link between geneticsand how your child may react to medical treatment? For example, how your child may react to medication."

Data collection

Data collection occurred from July 2011 until January 2012. Registered nurses on the postpartum unit asked mothers if they would be interested in hearing about the study. If mothers were willing to hear about the

study, the registered nurse informed the principle investigator or co-investigator. The principle investigator or co-investigator met with the parents, explained the study, answered questions, and obtained informed consent. The interviews were conducted in the mother's private room. The principle investigator (PI) and co-investigator conducted all interviews. Each interview lasted approximately 20 minutes. All interviews were audio taped. The interview progressed at a comfortable pace for the participants. Field notes about interactions and surroundings were transcribed immediately following the interview. Names of participants and other identifying information were removed from typed transcripts to protect confidentiality.

Data analysis

After removing participant's names and other identifying information all interviews were transcribed, checked against audio recordings and imported into NVivo (Version 9, QRS International Victoria Australia) for analysis. As a quality control measure the transcriptions were compared to the handwritten notes to determine their accuracy and consistency. Qualitative content analysis, an analysis of verbal and visual data oriented toward summarizing informational contents of data, was conducted with the goal of describing parent's knowledge of pediatric genetics [27]. The analysis of the data was a three stage process. Each interview was read and key terms and phrases that align with the research questions were identified. Analysis of these key terms and phrases were used to identify and describe categories. Finally, themes were identified on the basis of the categories. As each interview was examined, key words and phrases were modified. Descriptive statistics depicted demographic and frequency of categories.

Results

Of the 159 women approached in the primary study, 108 women declined to participate, 2 women did not respond to requests to hear about the study and 17 women were unavailable at the interview time. Thirty-two women completed the interviews [28]. Saturation is established when collecting and analyzing data revealed no new ideas or themes. Data saturation demonstrates the study has an adequate sample to demonstrate content validity [31]. Data were saturated at 29 interviews. No new comments, categories or themes emerged in the remaining six interviews. Sample demographics are described in table 1.

Two themes were identified: (1) parental lack of knowledge and misconceptions of genetics in healthcare and (2) parent's belief in the value of the genetics in healthcare. Parental source of genetic information emerged as an accounting of where parents obtained genetic information.

Parent's knowledge of pediatric genetics

The majority of parents, 46% (n=15), interviewed responded they had no knowledge of genetics. When parents were asked what they knew about genetics one mother said, "Not much really. [Nervous laugh]. I don't know a lot about it so I really can't say anything." In a mother-father dyad, one father said, "I've heard about it. That is all." Another mother said, "I don't know anything about genetics."

Some parents (27%, n=7) felt they had an understanding of genetics and its role in healthcare. As one mother said, "they usually do it to see what might happen to the baby. Like if they have down syndrome and stuff like that." Although most parents express a very basic understanding, two mothers seemed to have a greater understanding of genetics. This quote from one mother indicated she was knowledgeable about genetics and genetic testing. "I know they use genetic testing to help to diagnosis or to look for potential problems as far as developmental health issues that are passed down, things of that sort. I know they can use genetics to test for all different kinds of diseases and to find out if babies are carriers, or if they have dominant recessive traits that may be expressed."

Variable	Mean (Range), (n) Frequency
Maternal (n=32)	
Age range (years)	29.9 (19-40)
Education	
Secondary incomplete	(n=2)
Secondary	(n=7)
Some college	(n=6)
Associate	(n=1)
Bachelors	(n=9)
Masters	(n=3)
Doctorate	(n=4)
Ethnicity	
Black	(n=12)
White	(n=18)
Hispanic	(n=1)
Chinese	(n=1)
Marital Status	
Married	(n=23), 72%
Unmarried	(n=9), 28%
Gravida	
Primigravida	(n=8), 25%
Multigravida	(n=24), 75%
Infant Gender	
Male	(n=15), 47%
Female	(n=17), 53%
Paternal (n=23)	
Age range (year)	33.3 (23-50)
Education	
Secondary incomplete	(n=1)
Secondary	(n=4)
Some college	(n=2)
Associate	(n=1)
Bachelors	(n=9)
Masters	(n=2)
Doctorate	(n=4)
Ethnicity	
Black	(n=9)
White	(n=13)
Hispanic	(n=1)
Interviews	
Maternal only	(n=19), 59%
Paternal only	(n=1), 3%
Mother-Father dyad	(n=12), 38%

Table 1: Characteristics of Study Participants (n=32 mother, mother-father dyads)

When the parents who stated they had a limited or basic understanding of genetics (25%, n=8) were asked probing questions such as "If you thought about it, how do you think genetics could affect healthcare?" parents did not (or could not) expand on their answers. One mother in a mother-father dyad said, "Not much. All I know is you can get genetic testing done while you are pregnant so you can figure out what you are in for." Parents that chose to explain their answer were hesitant and unsure. One mother who works in healthcare said, "I don't know too much about genetic testing. But I know somewhat, a little, about the testing for down's syndrome. It is to see if the baby is going to have any type of problems, delays growing up, pretty much like a handicap baby." Another mother was uneasy and fearful about how genetics could be used in healthcare, "I know I have mixed feeling on it. I know that it could be useful to help…

like if my child got sick, if there were testing done. I just don't know, with the cord blood and everything. These kinds of things could be helpful. I don't…I am very uneasy when people know too much. I am afraid where it would lead to, like terminating pregnancies just based on what might happen when you are 10 years old."

Overall, parents have very little or no information about genetics. The parents that believe they have some information about genetics seem unsure if their information is correct. Parents do not seem to be comfortable with their understanding beyond the basics of prenatal testing.

Parental perceptions on the value of genetics in healthcare

Parental perceptions on the value of genetics in healthcare were mixed. Overall, parents felt genetics is valuable tool for the prenatal diagnosis of prenatal disease. One mother believes, "Genetics is used before birth to diagnosis stuff. It helps families understand what condition the child is in prior to birth." Another mother agrees stating, "They do genetics to see what will happen to babies."

However, parent's opinions about incorporating genetics into healthcare after the child is born are varied. Parents did not agree there could be a link between genetics and effective medical treatments. In a mother-father dyad, the mother felt "There is no such thing as a genetic link to disease." The father believed, "It is not a genetic link it is conditioning. It is like IQ. You are born with a range and what happens to you in school and life determines where you are in that range." When one mother asked the PI for a specific example, the PI proposed the scenario, did she think knowing her child's genetic information would help her understand how her child might respond to medication such as pain medication? The mother replied "I do not think there is a connection between things like genetics and pain."

Some parents were uncertain about the link between genetics and health. One mother said, "I do not see how." For one father it was the first time he thought about it, "I haven't considered it. I have no idea. Probably no". Another father said, "Yes, maybe there is a link. But I don't think there is any evidence." Only one parent felt there was a link between genetics and healthcare, "Yes I believe there is a link. I want to hear about that."

Parents in this study feel there is value in prenatal diagnosis of disease but parents are uncertain of the value of genetics after the child is born. Furthermore, parents are not in agreement about the link between genetics and health.

Source of pediatric genetic information

Parents interviewed received their knowledge of genetics from a variety of sources. Personal experience (n=8, 25%) or knowing someone who had genetic testing (n=4, 13%) provided an exposure to genetics but parents did not have addition information about the genetic test or experience. A mother-father dyad who has their DNA stored shared, "We had a swab. It tells you if you have a handful of diseases like diabetes and such. That is all we know." A mother from a different mother-father dyad told the PI, "My best friend had some genetic testing done because she is from a background that has a lot of risk for complications. They did a whole bunch of work up for that, but I don't know what. I don't know how she feels about it."

Parents perceived public media as a reliable resource for genetic information (n=3, 9%). The father from the last mother-father dyad shared, "I know very little except from what I get from the Syfy channel." Another mother said, "I don't know much. The stuff I hear on TV. Like you know, it's not really much, it is just they are using it for, like, cloning. That's the only thing I am really hearing about, cloning fetuses. Something I heard recently, like cloning the sperm and eggs and stuff like that. In case in one family something happens to one they have another." In a mother-father dyad, a father shared, "I am paranoid. I watch a lot of movies. In genetics, you get stuck with a bunch of needles and they use your blood for someone else."

Although the sources of genetic information are not mutually exclusive, the primary source of genetic information for parents in this study is personal experience, followed by knowing someone who has genetic testing, then the media. It is interesting that the media source identified is the Syfy channel and not an educational or documentary program or series. Parents seem unaware that genetic information presented informally through various media is not always correct.

Discussion

Results from this qualitative descriptive study may provide insights that will guide our endeavors to engage patients in future clinical genomic testing. Specifically, our findings may clarify parents understanding and expectations of genomic testing. These insights provide a platform from which to evaluate emerging genomic interventions for parents of healthy infants. The lack of parental knowledge, misconceptions surrounding genetic testing and genetic research demonstrates a need for parental education directed toward the role of genetics in health, illness, and pediatric genetic research. Findings describe parental knowledge of genetics, the sources that parents use to arrive at the knowledge and parental perception of the value of genetics in healthcare.

Parental knowledge

Parental lack of genetic knowledge was a consistent finding among study participants. Although most parents of healthy infants admitted to having no knowledge of genetics, parent's that felt they had some understanding were hesitant in their responses. Among the parents willing to expand their answers, parental responses were about genetic testing. Their responses indicated that genetic testing is only performed to reveal the presence or absence of disease. The parents talked about genetic testing as being absolutely diagnostic instead of reflecting the probability of developing a specific health pattern [32]. No parent discussed the influence of lifestyle or environment on their child's genome or their need to know more about genetics. The most compelling examples of decisions that may be influenced by parental knowledge of genetics are how genome wide sequencing may identify genetic contributions to disease [33] or how genome wide sequencing may be utilized to diagnosis disease in patients with indefinable diagnosis [34]. Parental misunderstanding of phenotype (such as obesity) and family history and how they may work synergically with genomics may prevent access to genomic discoveries [35]. The gap in parental knowledge may be a significant factor in parent's ability to consider the large amount of genetic information required when making healthcare decisions about their child.

There is a very complex nonlinear relationship between knowledge about and attitude toward genomics [36]. Although it seems intuitive that a public less knowledge about genetics will lead to less positive public attitudes about genetic interventions, the converse of that statement is not evidence-based [37]. In other words, the statement a better educated public about genetics, will have a more favorable response to genomic developments is not supported by evidence. While one study demonstrated increased knowledge about genetics was associated with increased acceptance of genetic testing [38] another study found more knowledge produced more caution and criticism about genetics [39]. Recent research concurs, suggesting that public knowledge of genetics may in fact result in a more discriminating public. Individuals may demonstrate a cautious attitude toward social, moral and sensitive issues, issues often highlighted in genetics [36,40,41]. In most studies, participants who were willing to consider genetic testing were committed because of an existing or at risk medical condition [41-43]. Supporting the premise that attitudes toward

genetics arise from perceived personal benefits and harms. [44,28].While public attitudinal research continues to include educational level as a demographic, current research suggests educational level is insignificant [44]. Our data examining the relationship between demographic identities and parental self-reported genetic knowledge is displayed in table 2.

Parental lack of genetic information may have contributed to parental uncertainly and wide range of expectations from the outcome of incorporating genetics into their child's healthcare. Misperceptions surrounding genetics and genomics often occurs from confusing consumer advertising or misleading media and may represent a concern for healthcare providers [45]. Adverse outcomes such as increased anxiety, false reassurance, or inappropriate use or omission of health care services could result from misconceptions and misleading representations of genetic tests [46,47]. Understanding parental misperceptions of genetics and genomics helps clinicians provide accurate information to patients and allows for informed consent about the risks, benefits and limitations of genetic testing [48].

Value of genetics in healthcare

Parents of healthy infants did not place a value on pediatric genetics unless they perceived it would aid in the diagnosis and treatment of prenatal disease. No parent expressed an understanding that genetics could identify health risks and provide an opportunity for evidence-based interventions to decrease those risks. Additionally, parents seemed unaware that genetic information could be used to promote health.

Previous research has documented interest [44,42,43] and raised concerns about the public's enthusiasm for genomic testing [47,49]. Data suggest while the public may have a fairly high familiarity of genetics and an interest in genetic testing, they do not understand or appreciate gene-environment interactions, disease penetrance or how individuals are stratified into genetic risk categories [36].

Our study found a deficit in parental knowledge of genetics was an important impediment to parents enrolling infants into genetic research. Thirty-two parents stated they would refuse to participate in genetic research or testing. The self-reported genetic knowledge level of the twenty-three parents (66%) who refused genetic testing or participation in pediatric genetic research ranged from no knowledge to some knowledge. Four of the parents who reported they were knowledgeable about genetics stated they would refuse to participate. The findings propose that if parents have some a priori knowledge of genetics they will be more willing to hear about a research study. Parents having little or no knowledge of genetics, stated they would not be interested in hearing about or participating in the study [28].

To understand and support to patient's responses to genomic testing, it is important to explore specific patient population's knowledge and perceptions of genomics [43]. McGowan et al. reported parents presenting in a genetics clinic to meet with a genetics specialist regarding their own or their child's health had favorable attitudes towards genetic testing. They viewed the diagnostic application of genetic testing as more valuable than health promotion and early recognition of genetic risk assessment. Participants in the study also voiced numerous concerns regarding the potential misuse of genomic results.

Recognizing patterns of disease that may indicate a possible genetic link, educating the family about the implications of a potential genetic susceptibility as a necessary part (not an add-on) during assessment, referring the family for counseling and health promotion conversations should be part of all dialogues with patients. To accomplish this nurses should augment their current practice by obtaining a multigenerational genetic family history for each patient, assessing all patients for potentially heritable conditions, providing referrals to genetic health professionals as needed, offering genetic testing when indicated, and considering an individual's genetic makeup in the selection of medications and treatments for that person [50]. One objective measure of these clinical applications may be an increase in public recognition and acceptance of genomic analysis for health prevention.

However, genetic literacy alone does not translate to public acceptance of genomic interventions. Critical reviews do not support the hypothesis of sustained behavioral change following the provision of genetic information [51-54]. Recognizing the value of genomics in healthcare is a necessary component of achieving genetic public health goals.

Genetics has tremendous application towards achieving public health goals. However, these goals cannot be achieved without genetic literacy

	No Knowledge of Genetics n (%)	Some Knowledge of Genetic n (%)	Feel They Understand Genetics n (%)
Education Level			
Some Secondary Education Up to Bachelor's Degree	9 (28%)	4 (13%)	1 (3%)
Bachelor's Degree	4 (13%)	1 (3%)	2 (6%)
Master's Degree	1 (3%)	2 (6%)	2 (6%)
Doctoral Degree	1 (3%)	1 (3%)	2 (4%)
Source of Knowledge			
No Source	11 (34%)	0 (0%)	0 (0%)
Unsure	0 (0%)	2 (6%)	0 (0%)
Friend or Family	3 (9%)	1 (3%)	0 (0%)
Personal Experience	0 (0%)	3 (9%)	5 (16%)
Media (Syfy Channel)	1 (3%)	2 (6%)	0 (0%)
Literature in Physician office	1 (3%)	0 (0%)	0 (0%)
Employment	0 (0%)	1 (3%)	1 (3%)
Formal Education	0 (0%)	0 (0%)	1 (3%)
Refused to Disclose	0 (0%)	0 (0%)	1 (3%)

Table 2: Relationship of Demographic Identities to Parental Self-Report of Genetic Knowledge n=32

and public acceptance of the value of genetic in health care. Research in health communication will be essential to encourage parental understanding and interpretation of role of genomics in healthcare [53,54]. Incorporating genetics in all healthcare activities will increase public exposure. Healthcare providers can participate in genetic-based and genomic-based practice activities, such as collecting family history, obtaining informed consent for genetic testing, and administering gene-based therapies. Healthcare has a critical role advocating for, educating, counseling, and supporting patients and families who are making gene-based healthcare decisions. Current and future research must establish evidence-based interventions to consolidate the substantial amount of information from whole genome sequencing to a manageable body of information to accommodate the variable levels of health literacy within the general public. Through research, access to and the ability to provide informed consent about genomic interventions can be encouraged [36].

Sources of Information

Sources of information are an important consideration when examining parental genetic attitudes and beliefs. Much of the information shared by the 32 postpartum mothers and mother-father dyads during the interview was inaccurate or obtained from questionable resources such as the Syfy channel (n=3, 8%) or friends or family who had a child that required genetic testing (n=4, 11%). The educational level of parents who utilized the Syfy channel ranged from no knowledge of genetics to some knowledge of genetics. Parent who received genetic information from friends or family that had a child that required genetic testing ranged from no knowledge of genetics to some knowledge of genetics. Parents with Master's or Doctoral degrees stated received their information from personal experience, formal education, employment or participation in a genetic study. Two parents with masters and doctoral degrees stated they had no knowledge of genetics. No parent reported receiving genetic information from a public educational source such as the Discovery Channel, museum, WebMD, or the National Library of Medicine health information for consumers. These educational programs may be perceived as "dry" and "boring" compared to the drama in the programming on the Syfy channel. Condit states that social experiences and technical knowledge have an equal influence on formalizing personal beliefs [44].

Limitations

An awareness of descriptive study limitations will help guide the interpretation of the study. The study reports on a small set of qualitative interviews conducted in a postpartum unit within an inner-city teaching hospital on the east coast of the United States. The heterogeneity with regards to the educational level and ethnicity of the sample was a concern. Although heterogeneity ensures a high degree of representativeness of all the strata or layers in the population [55], the sample in this study is too small to permit generalizability to a larger population. Moreover, some of our findings may be context specific and may not represent parental perceptives in other hospital settings. Socioeconomic status has been associated with differential awareness and interest in genetic testing, it is unclear whether interest or use differs by ethnicity [56,57]. To ensure studies emphasize different factors that affect parental knowledge of genetics, future research should utilize a larger sample size, include hospitals that serve a diverse community, establish associations, correlations or test hypothesis and report significance.

Additionally, the recruitment of mothers and mother-father dyads into genetic research immediately after birth may reflect a bias. Immediately after birth parents may be overwhelmed. Mother has just given birth and fathers may have participated in the delivery. The parents may be exhausted. Moreover, when parents are awake they are getting acquainted with their infant. Finally, immediately after birth, parents are exposed to a significant amount of new information about their infant. Parental participation in a genetic research study may be limited to parents interested in genetics. It is also possible that some probing questions were too general to illicit a response from some parents. Further research is needed to determine if education and approaching parents at a later well-child examination will result in more willingness to enroll infants in pediatric genetic research.

This research illustrates knowledge gaps and misconceptions in genetic information among parents of healthy newborns. The study findings suggest that parent's primary source of genetic information is informal media, anecdotal reports from friends, or personal experience. They do not seem to value the importance of genetics in healthcare other than prenatal testing. This is troublesome because parents need to be genetically literate in order to make informed health care decision for their child.

Data from this study can assist clinical nurses when they develop an educational plan to inform parents about the role of genetics in healthcare. Nurse scientists can utilize the findings to help with recruitment, study design; and assist parents in understanding the risks, benefits and value of enrolling their healthy infants in pediatric genetic research.

Conclusion

One of the long term goals of President Obama's Precision Medicine Initiative is to increase the ability of physicians to use patients' genetic information as part of routine medical care for the prevention and early recognition of medical conditions [58]. We were most surprised to find highly variable responses and limited enthusiasm for clinical genomic testing among parents of healthy infants. These parents expressed multiple concerns regarding clinical genomic testing that must be considered as new genetic testing options are offered to patients.

Although our study is limited by a specific but heterogeneous sample, and since very few parents of healthy infants are interested in genomic testing, future research examining the knowledge and misconception of this population can provide insight into responses to new genetic interventions. The views expressed by parents of healthy infants provides important references for clinicians interested in adopting genomics in clinical practice in precision medicine.

Conflicts of Interest and Source of Funding

The authors declare no conflict of Interest.

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