An Exploration of the Art of Prenatal Genetic Counseling in Catholic Hospitals

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ABSTRACT

An Exploration of the Art of Prenatal Genetic Counseling in Catholic Hospitals

A thesis presented to the Graduate Program in Genetic Counseling

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Religious directives govern healthcare offered at Catholic hospitals, including some that outline what prenatal testing should be offered to pregnant women. These directives appear to be in conflict with prenatal testing that is typically offered during a prenatal genetic counseling session. Research has explored how physicians navigate the Catholic hospital directives, but less is understood about the experiences of prenatal genetic counselors working in Catholic hospitals. The purpose of this study was to explore the experiences of prenatal genetic counselors working in Catholic settings in order to understand how the religious directives affect their counseling. Ten genetic counselors that see prenatal patients in a Catholic setting were recruited from an online listserv to participate in a semi-structured phone interview. The major topics addressed included what prenatal testing is offered during a prenatal session, how aware genetic counselors are of the religious directives, and how they believe those directives affect their sessions. Thematic analysis of the interview transcripts was performed in ATLAS.ti (v.7.5.4) and five themes were identified: (1) the pregnancy options genetic counselors offered to patients including testing options as well as specialist referrals, (2) navigation of regulations imposed by
the religious directives, (3) how genetic counselors handled any conflict that arose from their duties as a genetic counselor and their duties to uphold the religious directives, (4) patient support as a priority, and (5) job satisfaction. Genetic counselors reported that the religious directives did affect what and how various procedures were discussed, particularly termination of pregnancy. However, despite this, the findings of this study are positive indicating genetic counselors felt that they could perform their jobs and use their own jurisdiction of how to apply the religious directives appropriately. They also felt that despite the religious directives, patient care was not compromised.

**Keywords:** religious directives, terminations, prenatal genetic counseling, Catholic hospitals, navigating conflict, patient care, support
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Introduction:

As a profession, genetic counseling is designed to assist patients in understanding and adapting to the medical, emotional, and familial implications of the genetic components of disease (NSGC, 1995). While some genetic counselors choose to pursue more non-traditional work, such as research positions, working with insurance companies, or industry many genetic counselors pursue roles in clinical practice. One of these subspecialties is prenatal genetic counseling. While all genetic counselors help patients in understanding the genetics of a disease, prenatal genetic counselors focus on discussing the genetics involved in a pregnancy. Much of this work surrounds offering patients various screening and diagnostic tests to provide the parents with as much information about the genetics of the pregnancy as possible (Hoskovec, 2015). There are several forms of screening in the prenatal setting. The first form of screening is an ultrasound of the pregnancy, which gives providers information about how the fetus is growing and developing, as well as information about the overall structure of the fetus. An abnormal ultrasound would indicate some part of the fetus is not growing or developing as one would expect and warrants a meeting with a prenatal genetic counselor. Other screening tests offered include blood tests, such as the quad screen, which assesses different hormones levels in the mother’s blood. Hormone levels outside of normal ranges can indicate a genetic abnormality in the pregnancy. More recently, another blood test typically offered is noninvasive prenatal genetic testing (NIPT), which measures placental DNA in the mother’s bloodstream. Similar to the quad screen, DNA levels outside of the normal range can indicate a genetic abnormality in the pregnancy. Lastly, some genetic counselors offer couples carrier screening based on
ethnicity. When we think about genetic disorders that may affect a pregnancy, many of them are autosomal recessive. This means that there needs to be a mutation in both copies of the same gene to cause symptoms of the disease. Being a carrier for one of these conditions means that a person has a mutation in one copy of their gene, but their other copy functions normally. Being a carrier of a disease typically does not present medical concerns, but if two people are carriers for the same disease, they have a 25% chance of having a child affected with that disease. We know that some ethnicities are at an increased risk to carry mutations for specific disorders. Couples can be offered carrier testing through a prenatal genetic counselor to ensure that the fetus is not at increased risk for a particular disorder.

Prenatal genetic counselors will also offer diagnostic testing, such as chorionic villi sampling (CVS) and amniocentesis, which can definitively indicate a genetic disease (Abramasky, Rodeck, 1991). Clinicians usually perform CVS between 11-14 weeks of pregnancy and involves obtaining a sample of the placenta to assess the genetics of the placenta. Knowing the genetic makeup of the placenta typically indicates what the genetic makeup of the fetus is because the fetus and placenta typically arise from the same cells. Clinicians usually perform amniocentesis between 18-20 weeks of pregnancy. In this procedure, a small amount of amniotic fluid is obtained from the pregnancy, which can be analyzed for chromosome abnormalities and other genetic disorders. Both of these procedures can be used to collect fetal cells to assess for any chromosomal aneuploidies or specific genetic disorders in the pregnancy.

All screening during pregnancy is optional and patients may decline testing. However, if parents do opt for any combination of the screening and diagnostic testing, the prenatal genetic counselor is typically the one who coordinates the testing and communicates those results back to the patient/couple. The vast majority of the time (97%), the screening results come back
normal (Centers for Disease Control and Prevention, 2008). However, sometimes the results are abnormal and further discussion may be required to talk about the prognosis and options for the pregnancy. Discussing abnormal results to expecting parents can be sensitive. Genetic counselors are trained to present a diagnosis in a way that paints a realistic picture of the diagnosis, while trying not to limit the potential of the life of the child in totality. As part of the discussion of genetic testing during pregnancy, particularly in the cases of an abnormal result, genetic counselors may guide the discussion about the available options: continuing the pregnancy, meeting with specialists or a social worker as needed, placing the child up for adoption, or termination of the pregnancy. In many states, terminations are legal up to 20-24 weeks of the pregnancy, although eight states in the country and the District of Columbia have no specific laws prohibiting terminations at any point in the pregnancy (Guttmacher Institute, 2016). Some parents choose the option of termination, while others opt to continue the pregnancy. Those that decide to continue or place the child up for adoption often do so because they have ethical or moral qualms about termination or because they feel that despite any chromosome conditions, they have the capacity to care for a child with special needs. Those that decide to terminate often do so because they do not feel that they have the capacity to care for a child with a severe handicap, or based on the severity of the diagnosis, they feel that it would be a more compassionate decision to end the pregnancy rather than let the child suffer for what is often a short life. A discussion regarding termination of pregnancy is often part of a genetic counseling session, especially in situations where a diagnosis has been made in the pregnancy.

Both federal and state courts widely debate the ethics of pregnancy terminations. The first law to legalize terminations was *Roe v. Wade*, a case before the Supreme Court in which a woman seeking a termination in Texas brought suit against the state of Texas claiming the laws
criminalizing terminations were against her constitutional rights. In a 7-2 decision, the Court ruled that the Texas statute violated her constitutional right to privacy, thus legalizing terminations as lying within a woman’s zone of privacy. After the Supreme Court’s landmark decision regarding abortion in *Roe v. Wade* in 1973, subsequent cases have come before the Supreme Court to try to limit the legality of abortions (“Roe v. Wade”, 1973). Most recently, in 2016, the Supreme Court ruled that the Texas standards for abortion clinics were too stringent, essentially, limiting women’s access to terminate a pregnancy (de Vogue, Kopan, Berman, 2016). While the courts continue to debate how the laws should permit or limit abortions, there are several institutions that have unwaveringly opposed abortions, one of them being the Catholic Church. Based on religious and ethical teaching, the Catholic Church’s stance on abortion is strict. According to the Catechism of the Catholic Church, the Church acknowledges the sanctity of life from the moment of conception until death. As such, abortions are not permitted, as a deliberate termination of a pregnancy would undermine the sanctity of life (Libraria Editrice Vaticana, 1992). The Catholic Directives, a set of guidelines for Catholic hospitals that the U.S. Conference of Catholic Bishops (USCCB) issues and enforces by local bishops, states, “Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted” (USCCB, 2009, Directive 45).

Moreover, there are additional Directives that outline when it would be appropriate to offer diagnostic testing during a pregnancy. The Catholic Church allows for prenatal diagnosis in some situations saying, “prenatal diagnosis is permitted when the procedure does not threaten the life or physical integrity of the unborn child” and as long as it is not, “undertaken with the intention of aborting an unborn child with a serious defect” (USCCB, 2009, Directive 50). The
invasive procedures themselves are morally neutral, but healthcare workers in Catholic hospitals must deduce the intent of the mother before going forward with testing. If a mother were sure that she would never consider terminating the pregnancy based on the test results, then the testing is permissible. However, if the mother is uncertain about what she would do with abnormal results, the physician should not proceed with testing because her uncertainty would prove that the mother had at least entertained the idea of a selective termination, which is always morally wrong according to the Catholic Church (Bringman, 2014).

With the Catholic Church limiting so many procedures, particularly in the area of prenatal care, it begs the question of how prenatal genetic counselors conduct sessions in a setting that at times appears to be in direct contradiction with the profession. Many questions arise when thinking about the practice of prenatal genetic counselors in Catholic hospitals; such as do the prenatal counselors discuss terminations in sessions? If a patient desires a termination, how does the genetic counselor handle the situation? There are Catholic hospitals in all fifty states and according to the official Catholic directory, one out of six patients in the U.S. is being cared for at a Catholic hospital (Catholic Health Care in the United States, 2016). With these hospitals being so common, up to 17% of pregnant women could be receiving their prenatal care from prenatal genetic counselors who may not be able to discuss all pregnancy options due to the institutional rules of the hospital.

To date, there are no studies that give a clear picture of how a prenatal genetic counselor specifically might navigate some of these issues. There are several studies that have analyzed how other medical professionals, such as OBGYNs, feel about working in Catholic hospitals, but to our knowledge, a study has never looked at prenatal genetic counselors. This study attempts to
bridge the gap in the literature and to understand more clearly the experience of a prenatal genetic counselor in this setting.
Methods:

Study Design

This study utilized a qualitative, phenomenological approach to gain an understanding of the experience of working in a Catholic hospital as a prenatal genetic counselor (Creswell, 2013). The student researcher conducted semi-structured phone interviews with ten prenatal genetic counselors that reported working in a Catholic setting. These interviews consisted of a series of open-ended questions that invited participants to talk about their work experiences. Close-ended questions were also included to gather demographic information. This approach allowed participants to share personal stories, expand on experiences, and convey their feelings, which allowed us to capture the essence of the experience of seeing prenatal patients in a Catholic setting. Upon expedited review, Brandeis University Institutional Review Board approved this study.

Study Population

The student researcher recruited participants through the National Society of Genetic Counselors and the American Board of Genetic Counselors through an email sent by the organizations to their member distribution lists (Appendix A). The recruitment materials encouraged interested individuals to email or call the student researcher directly. Additionally, if a genetic counselor saw the recruitment notice and knew of someone who might be eligible to participate, they were encouraged to forward the recruitment notice along to genetic counselors that might be eligible. We received emails from twenty-two individuals who expressed interest in participating, twenty of whom met eligibility criteria, and the first 10 eligible respondents were
enrolled in the study. To be eligible for the study, participants needed to: be certified genetic counselors, either currently work in a Catholic hospital or have worked in a Catholic hospital within the past five years, work within the United States, and see prenatal cases in a Catholic institution on a consistent basis. Once the student researcher determined an individual was eligible, she scheduled the interview and emailed an information document for the participant to read (Appendix B). Before each interview, the student researcher went over a study information document with the participant and obtained verbal consent to proceed.

Data Collection

The author conducted and recorded phone interviews with all participants and recorded the interviews using the freeconferencecalling.com service, which all participants agreed to during the informed consent process. The author conducted all interviews utilizing the same interview guide (Appendix C), which consisted of open-ended questions targeting personal experience with testing options in Catholic hospitals, terminations in Catholic hospitals, and emotions surrounding their experience working in this setting. The order and wording of the questions as well as the length of time spent on each question varied across interviews. The interviews ranged from 22 minutes to 34 minutes in duration and an outside transcription service transcribed each. All participants received a $25 Amazon gift card as a token of appreciation for participating. The student researcher coded all audio recordings and interview transcripts and stored them on box.com, an encrypted site hosted by Brandeis University.

Data Management and Analysis

All interview transcripts were de-identified and imported into ATLAS.ti (version 7.5.4) for analysis. The student researcher carried out all coding and thematic analysis was performed.
Results:

The author interviewed a total of ten participants, which consisted of ten women who are currently working or have worked in a Catholic setting within the past five years. Their experiences differed in how many years they have worked in a Catholic setting, what specialties they work in, and what region of the country they work in (see Table 1). The amount of total years working as a genetic counselor ranged from three years to thirty-two years. The amount of years working in a Catholic setting ranged from two years to twenty-five years. Six participants worked in the Midwest, regions 3 and 4 from the NSGC regions. The other four participants worked on the East coast encompassed by region 2. The researcher assigned participants a letter to protect their privacy.

Table 1: Demographics of Participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Total years working as a genetic counselor</th>
<th>Total years working in a Catholic hospital</th>
<th>Patient population</th>
<th>NSGC region they worked in at the Catholic hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant A</td>
<td>9</td>
<td>8</td>
<td>Prenatal only</td>
<td>Region 4</td>
</tr>
<tr>
<td>Participant B</td>
<td>3.5</td>
<td>2</td>
<td>Prenatal only</td>
<td>Region 2</td>
</tr>
<tr>
<td>Participant C</td>
<td>3</td>
<td>2</td>
<td>General</td>
<td>Region 2</td>
</tr>
<tr>
<td>Participant D</td>
<td>16</td>
<td>13</td>
<td>Prenatal only</td>
<td>Region 4</td>
</tr>
<tr>
<td>Participant E</td>
<td>32</td>
<td>13</td>
<td>Prenatal and cancer</td>
<td>Region 4</td>
</tr>
<tr>
<td>Participant F</td>
<td>10</td>
<td>8</td>
<td>Prenatal and cancer</td>
<td>Region 3</td>
</tr>
<tr>
<td>Participant G</td>
<td>25</td>
<td>25</td>
<td>General</td>
<td>Region 4</td>
</tr>
<tr>
<td>Participant I</td>
<td>8.5</td>
<td>8</td>
<td>Prenatal only</td>
<td>Region 4</td>
</tr>
<tr>
<td>Participant J</td>
<td>3.5</td>
<td>3</td>
<td>Prenatal and cancer</td>
<td>Region 2</td>
</tr>
<tr>
<td>Participant K</td>
<td>10</td>
<td>7</td>
<td>Prenatal only</td>
<td>Region 2</td>
</tr>
</tbody>
</table>
Upon interviewing this cohort, five main themes emerged: (1) the pregnancy options genetic counselors offered to patients including testing options as well as specialist referrals, (2) navigation of regulations imposed by the religious directives, (3) how genetic counselors handled any conflict that arose from their duties as a genetic counselor and their duties to uphold the religious directives, (4) patient support as a priority, and (5) job satisfaction.

**Prenatal Options for the Pregnancy**

We asked participants about the patient population they typically counseled, as well as the screening/testing options they offered. Half (5) of the participants reported they saw both high and low risk patients while the other half saw only high-risk patients. High-risk patients included those that were advanced maternal age and those who had an abnormal ultrasound finding. While the participants saw different patient populations, all mentioned the availability to offer both screening and diagnostic testing. One participant notes the following testing options:

“...first trimester screening, cell-free DNA, CVS, amnio, and if they have prenatal diagnosis we talk about karyotype versus microarray, versus if there is something specific, then we talk about single gene panel. We offer carrier screening to everybody, and other things we might order are blood carrier type on mom.”

In addition to these testing options, seven of the ten participants also explained that they would refer their patients to specialists such as pediatric cardiologists or pediatric neurologists for a more complete picture of the condition affecting the baby and what the prognosis might be in the event of an abnormal finding. Among those counselors who were involved in referring patients with affected pregnancies to a specialist, the majority (5/7) noted that these specialists were located outside of the Catholic hospital. As one counselor pointed out, the size of the hospital was a main reason for the outside referral to specialists:

“So, yes, we refer to specialists, and usually the specialist is at an outside hospital because the Catholic hospital is just so small. Like, we would be referring to a pediatric cardiologist or pediatric neurosurgeon or something like that and there just aren’t any at the hospital. So, we refer to the larger academic institutions.”
Among those counselors able to refer their patients to an in-house specialist (2/7), they were limited by the specialist type. Both mentioned that they were able to coordinate cardiac referrals within their hospital, but if it was anything other than cardiac, their patient needed to be referred outside of the Catholic hospital. One participant commented on the availability of a visiting cardiologist for their patients needing fetal cardiac evaluations, stating:

“...we would have a cardiologist that actually came to our office, so we had fetal echo days, and so those would be more in-house. But then, of course, if they needed to see neurosurgery or nephrology, or anything else, those would be referred out, and made by our-we had like a fetal care coordinator, who would coordinate all those appointments.”

Navigating Religious Directives & Hospital Regulations

We wanted to understand how genetic counselors are impacted by the Catholic Directives governing their hospital, and how they affect counseling sessions. We asked all participants if they were aware of the religious directives at their hospital and only four genetic counselors were aware of written religious directives. Many participants (6/10) commented they were never told to follow any specific Catholic directives. As one genetic counselor who was unaware of the religious directives noted:

“If there are actual written guidelines in place, no one has ever told me about them. But the doctors that I work under there are aware of the –like we write in our consult notes that get signed by the doctors afterwards that we discussed all pregnancy management options, including pregnancy termination. There are no secrets.”

While the majority of participants were not aware of the religious directives, one counselor mentioned that she specifically had to sign a paper saying she would uphold the religious directives.

“So that gave me more pause at that point about the conversation that could be had and I guess I struggled more with how to present and when to present when I signed my name to a piece of paper that said I would adhere to the religious directives of the hospital.”
As evidenced from this quote, she felt that signing the religious directives affected the way she presented certain information, such as specific information regarding termination.

Because termination is so strictly regulated in the Catholic setting, many of the participants discussed how the regulations affected how termination was presented in a session. All ten participants agreed that termination was brought up in some capacity within the session when warranted, although the specifics surrounding the option differed from participant to participant. Two counselors said that they could not discuss termination on their own volition, but if a patient brought it up as an option, they were allowed to engage the patient in that conversation. As one counselor put it:

"The strategy that we had as a department was that, since we were situated in a Catholic hospital, we were not to propose the idea of termination. However, if the patient brought it up to us, then it was okay to discuss."

Another counselor also mentioned that although she could not discuss the specific details about termination procedures, she could discuss the psychosocial aspects of terminations if a patient asked about it as an option.

"And basically we could explore it from a psychosocial standpoint. But if a patient was found to have an anomaly, we couldn't say, okay, your options are you can terminate your pregnancy or you can consider hospice or palliative care. So if the patient brought it up, certainly we were allowed to explore it from a psychosocial standpoint."

One counselor said that while she was not always the one to bring up the option of termination, but somebody always brought it up so the patient always knew it was a legal option to choose.

"So it [the option of pregnancy termination] would always be brought up. I would say, we worked under six different physicians, who I feel like would bring that up in different levels. I think I felt very confident that it was always mentioned at one point or another, whether it was always by me, wasn't always the case."

Other counselors expressed that they felt they had the freedom to talk about terminations including all of the specifics of the procedures because no one had told them otherwise. As one counselor put it:
“Nobody ever told me that I couldn’t [discuss all pregnancy options, including termination]. Nobody ever sat in on my sessions to tell me otherwise. I guess I could by virtue of not ever being told I couldn’t.”

In fact, three counselors expressed that they felt some freedom from the strict regulations surrounding termination because management took a “don’t ask, don’t tell” stance on this topic.

“I would say management took the stance more of don’t ask, don’t tell kind of thing. We understand that this may be a topic that is brought up and you understand that our hospital does not perform this procedure.”

While all of the counselors admitted that termination was discussed in some way during sessions, four of them also noted that when documenting the session afterwards, they had to use vague language in the clinical note so as to not raise any red flags. As one counselor described:

"The only caveat was that we had to be pretty careful about language we put in our clinic notes talking about termination. So, what we sort of wound up saying is just kind of the patient may elect to not continue the pregnancy is kind of how we worded it. So, we don't say, patient was offered a termination."

Out of the ten participants, they all said that terminations were never done in house at the Catholic hospital where they worked. There were two major ways to deal with the fact that terminations were not done in-house: the genetic counselor would either refer the patient back to their obstetrician or they would refer their patient directly to a facility that did do terminations. One counselor directly mentions this, saying:

“We just would not perform the procedure in the hospital. We would provide them with a name of a reputable center where we could recommend that they go for the procedure”.

Out of the ten participants, seven noted that they would refer patients to another site that would perform the termination while three of them noted they referred the patient back to their OB. If they were referring a patient directly to another facility, the counselor could be involved in setting up the appointment and giving the patient information about the facility. However, one counselor noted that if they were referring the patient back to their obstetrician, they had to dissociate from the process and could not provide the patient with any additional information:
“But when it came time to, if that was their final decision, we had to refer them back to their OB, and then the OB was responsible for helping them designate the clinic for a patient to go to, so we had to be completely dissociate with that process.”

Even though none of the Catholic settings performed terminations, nine out of the ten participants said there was a competing MFM practice in the area for the patient to go to so the patients were not limited to access of termination based on geography. Only one participant admitted there was a limitation to access because of geography. She said:

“There are no competing MFM practices. In the immediate area, you would have to drive, the very minimum amount would probably be an hour and 15 minutes to get to another MFM practice.”

**Conflicts Arising from Religious Directives**

The third theme that arose from the participants is whether or not the genetic counselors felt a conflict between their responsibilities as a genetic counselor and their responsibilities of upholding the religious directives. As the previous theme illustrates, there are differences in prenatal care offered at a Catholic hospital versus a non-Catholic hospital, particularly surrounding the option for termination of pregnancy. Of the ten participants, eight of them claimed that they did not feel conflict between their duties to inform their patients of options and to uphold the religious directives. One participant noted that she did not ever feel conflicted because of the collaborative way she worked with a physician:

“I really haven’t felt conflicted, and probably because we work collaboratively with the physicians, who really can attend to the mechanics of the discussion about the differences between a D&E, or an induction versus whatever. And those kinds of things are better coming from a physician anyways.”

Another participant felt that this conflict never arose because despite the regulations surrounding terminations, she felt she had the freedom to explore the topic if necessary:

“I never did feel conflicted, because I felt like I knew when taking the job with a Catholic facility, even if there were certain guidelines or boundaries that I obviously was agreeing to adhere to. But I think the difference for me was, again, that it was never a topic that I couldn’t explore, if needed. So I never felt like any patients were jeopardized by not directly being very blunt and saying, termination is an option. You could always explore that topic and make
On the other hand, two of the counselors did feel that the religious directives conflicted with their responsibilities and were a barrier during the counseling sessions. One counselor expressed worry that some patients left not fully understanding all of their options because she had been too vague about the option of termination:

“But I definitely feel like there was a barrier in some cases where I was trying to say, well, there are things that people do that were not discussed. Perhaps some of them didn’t realize that [termination] was an option and that perhaps it was something that they could consider if they wanted to”.

Another counselor noted how uncomfortable she felt about the conflict. She also alludes to the fact that it was frustrating to her that she could not be more of an advocate for her patients who were seeking out a termination.

“I think there’s definitely a slight conflict. I mean, even know knowing that we’re within this building and that topic is, at least to some degree taboo. So it’s sometimes a struggle for these patients [seeking terminations] because there are not good resources for them locally. And it’s tough to advocate for them sometimes given the conservative nature of the area. It’s just not an option for these patients to have a termination done in a hospital setting, they have to go to a clinic.”

**Patient Support/Care**

The fourth theme that arose from speaking to these genetic counselors is how the genetic counselors were able to support their patients despite the regulations put in place by the hospital. Eight out of the ten participants agreed that patient care did not suffer because of the regulations. Despite having to be cautious about how to present the idea of terminations, one counselor notes that she did not feel like her patients left with wrong or misleading information about termination.

“Like I said, I don’t think patients were ever slighted or misinformed or misled in any way based on seeking care at the Catholic hospital versus one of the academic ones.”
Additionally, in the instances when there was a conflict between their duties to the patient and their duties to the hospital, counselors commented that they always sided with the patients.

“I sometimes felt conflicted between the religious directive and my duty to the patient. But ultimately, I feel like I always sided with duty to the patient versus adherence of the religious directives.”

Nine of the ten participants believe that working in a Catholic hospital provides a supportive community for everyone to explore spirituality and religion and that actually enhanced patient support. One of the participants elaborated on this spiritual environment, mentioning that it was an expected part of patient care.

“Being in a Catholic hospital there is such a focus on attending to the spiritual and emotional needs of the families, and it’s awesome to be able to do that, regardless of what their religious background is, or their choices are. So, it’s just a facility where it’s expected that you do all of the touchy-feely, and that is just as important as their vitals and post-surgery care.”

Even among the participants who self-identified as not being that religious themselves, they still felt the religious aspect of the hospital could provide an extra layer of support in sessions. One counselor described it as being a part of an open, supportive community.

“I think it was a nice sense of community overall. I’ll be honest, I’m not religious myself. My family is Roman Catholic. I was kind of raised Catholic, but I don’t practice. So for me, it was like a personal investment that I had in being there. But they were really very open and receptive to people of all different faiths. It was something that I liked to see, that everyone was asked about their faith. They made their best effort to incorporate faith into discussions about medical decisions when possible, and it really developed a nice sense of community around the hospital that everyone can come here and feel like they can discuss their religion, which I think should be a good option for any patient, regardless of how they identify.”

**Job Satisfaction**

The last theme that arose from this study was how satisfied the genetic counselors were working in a Catholic setting. First, the majority of the genetic counselors (9/10) have spent the majority of their career involved in a Catholic setting. This is particularly striking in the genetic counselors that have practiced for decades. While all of the genetic counselors had some frustrations with their working environment, few of them reported frustrations that were large
enough for them to consider leaving their jobs. Additionally, when asked what the most frustrating part of working in a Catholic hospital was, seven of the ten participants did not mention the religious directives or the slight conflict between the duty to the patients and the duty to the hospital as being the most frustrating. Three counselors mentioned the most frustrating part was related to a lack of administrative organization or a lack of desired medical benefits. One counselor commented that it was her personal health benefits that were the largest issue:

“And this has nothing to do with actually counseling patients. But I will say that my medical benefits were actually somewhat of a problem. Like, oral contraceptives, they don’t cover. So I was paying out-of-pocket for a long time.”

There were three counselors who felt that the conflict between hospital policy and their duty to the patient was the most frustrating part of working in this setting.

“I think, unequivocally it’s just you want to make sure that someone’s aware of all of their options, and did they fully understand me, reading between the lines. Like I don’t like to make assumptions, and I’d feel better if I could be direct.”

But even for these three counselors, no one expressed that they were so unhappy with these conflicts that they were searching for a new job. Overall, the counselors were satisfied in their positions, and six out of the ten counselors thought their experience in a Catholic hospital was not different than working in a secular setting.

“I guess my takeaway is not that much is different than when I practiced at a different hospital. I would say on a day-to-day basis, there is virtually no difference from what I would do at another facility.”
Discussion:

The phenomenological approach employed in this study revealed that overall, prenatal genetic counselors working in Catholic hospitals seemed satisfied with their position and were not restricted with regard to testing and pregnancy options they were able to discuss in their sessions. While they do have to work within the regulations of religious directives, they did not feel like their experience of working in a Catholic hospital is drastically different than what their experience would be like if they were working outside of a Catholic setting. Moreover, they did not feel like patient care suffered as a result of the restrictions of the religious directives as evidenced from the patient care/support theme. This is significant not only for genetic counselors working or considering working in a Catholic hospital, but also for the patients who receive their prenatal care at Catholic hospitals. Especially in areas where there may not be another local hospital option, it is reassuring to know that genetic counselors are able to provide adequate genetic counseling services for their pregnancy care. This study may help dispel some preconceived notions of how religious directives may impact a prenatal genetic counseling session by providing an analysis of actual genetic counselor experiences. Similarly, patients may also have preconceived notions that they cannot discuss terminations or diagnostic testing because of the Catholic nature of these hospitals. This study shows that there are differences between healthcare in a Catholic hospital and a non-Catholic hospital; the most significant difference being that Catholic hospitals do not perform terminations in house. However, these differences do not deter genetic counselors from prioritizing patient needs and offering any support the patient may need whether it is a diagnostic test, a referral to another institution or
clinic for a termination, or pastoral care. In fact, one surprising positive from this study is how many genetic counselors agreed that the Catholic aspect of their work environment gave them the opportunity to emotionally and spiritually support their patients. Not only was it more readily available because of working in a religious hospital, but some genetic counselors noted that it was an expectation to discuss spirituality. And based on counselor reports, it seemed that patients appreciated that the genetic counselors were willing to go to those places with them and provide support for them.

While the most significant difference between Catholic hospitals and other institutions is the availability of termination, a few of the genetic counselors noted that the religious directives did play some role in their thoughts and feelings about when and how to present termination as an option. There were counselors who experienced conflict between the directives and their duties to the patients. There were also counselors who noted that they could not be direct about bringing up termination or had to skirt around what they documented in their medical record after their counseling sessions. Genetic counselors also reported having to be more cautious and creative in how they discuss certain options in sessions because of the religious directives. This theme of conflict is important to remind genetic counselors who may consider working in a Catholic hospital to be realistic about how they might work within the hospital’s regulations. Most of the counselors were positive about their experiences in Catholic hospitals, but the religious directives do exist. Because of their existence, conflicts between the hospital’s religious directives and the counselor’s responsibility to their patients may arise. For prenatal counselors who believe termination should always be discussed and available regardless of circumstance, these counselors should understand that the religious directives can pose a barrier to how upfront they can be about the option. However, according to this study, there is often a way to discuss it
in some capacity. For prenatal counselors who may not always be comfortable discussing terminations because of their own religious or moral beliefs, a Catholic hospital may be a good setting to provide prenatal care to patients.

There appeared to be a marked difference of responses based on what region of the country the genetic counselor was in. The genetic counselors that worked in regions 3 and 4, which encompasses the Midwest of the country, noted more often that the religious directives did affect how information was presented. These counselors were the ones who could not bring up the subject of termination on their own volition, could not discuss the specifics of the procedures of termination, and signed a piece of paper promising to uphold the religious directives. These geographical differences may be contributed to the fact that politically, the states encompassed within regions 3 and 4 are more often conservative than states in other regions. While, counselors more often noted that the religious directives shaped their sessions in these regions, they also noted that due to the self-reported conservative nature of the area, patients did not often consider termination an option. One of the counselors who had been working in a Catholic hospital in this area for about a decade said she could think of about only ten cases where the patient had desired a termination. Even though genetic counselors are more conscious of the directives in these regions, they did not feel like patient care suffered because it is not a procedure that many of their patients would have considered.

Moreover, while these religious directives are in place and counselors understand that they apply to Catholic healthcare, they also note that these directives are somewhat fluid and could be interpreted on a case-by-case basis. This is evident in the way that counselors brought up the idea that many of their administrators use a “don’t ask, don’t tell” mentality when it comes to what goes on during a session. Additionally, all of the counselors offered diagnostic
testing despite the religious directive that stipulate when diagnostic testing should be offered. According to Directive 50, diagnostic testing such as an amniocentesis should not be used if the mother is going to use this information to choose to terminate (USCCB, 2009, Directive 50). However, none of the counselors mentioned that they had to ascertain the mother’s intentions before offering diagnostic testing. This theme of prenatal options that are offered to patients shows that counselors are able to use their own prudence to interpret and apply the directives. While the theoretical conflict between the Catholic directives governing the hospital and the genetic counselors seemed substantial based on the specific wording of the Directives, it is promising that the participants we interviewed did not feel conflicted and could focus on their duty to their patients.

Another positive outcome from this study is that, generally, the counselors had worked in a Catholic setting for the majority of their careers. This speaks to the idea that counselors in this setting tend to be satisfied with their jobs. While there are counselors who expressed frustration regarding aspects of their work as with any position, no one was so deeply perturbed by the religious directives that they felt like they could not continue working in a Catholic setting. A few counselors have not spent all of their time in a Catholic hospital and some worked in a Catholic hospital but then moved to another hospital. These moves were not due to dissatisfaction or frustration at the religious directives. Rather, these counselors were often relocating. Although several counselors have switched jobs, working in a Catholic hospital and the regulations that may come along with that, did not appear to be a driving factor in their job changes. This suggests that these genetic counselors’ job satisfaction is not influenced by a conflict between the duty to inform patients as a genetic counselor and the religious directives.
This study has several limitations, including small sample size, selection bias, and a limitation of diversity in the participants. Only ten individuals were interviewed due to time and budget constraints. Since this is a small, qualitative study, findings are not generalizable to all prenatal genetic counselors or all Catholic hospitals. We recruited participants through the NSGC and ABGC listservs, and we do not know what motivating factors drove their participation, which may lead to selection bias. It may be the case that genetic counselors that are not satisfied in a Catholic hospital did not want to discuss their experiences. Additionally, there were no representative participants from region 1, 5, or 6, which limits the diversity of the group and may have skewed results.

As far as we know, this is the first study to look closely at the experience of prenatal genetic counselors in the Catholic hospital setting. Given the prevalence of Catholic hospitals nationwide it is useful for our field to understand how, if at all, patient care is affected. Further investigation of this population could potentially provide more information of how counselors are navigating working under religious directives. We hope this pilot study will spark the interest of researchers and serve as an inspiration for larger and more focused studies. It might be useful to study differences in counselor experience across a larger group and see how those experiences differ based on region. Additionally, it was interesting that despite the potential restrictions posed by the Catholic directives, the genetic counselors in this study felt as though they are able to present all of the options and patient care does not suffer. It would be interesting to hear the perspective of any genetic counselor involved with patients who are referred outside of the Catholic hospitals as well as the perspectives of patients themselves that end up seeking pregnancy termination outside of the Catholic hospitals to see if they matched with the impressions of our participants. Additional studies will help the profession understand the
experience of working in a Catholic hospital as a prenatal genetic counselor, which may in turn lead to more comprehensive support for these counselors.
Conclusion:

The religious directives dictate how Catholic hospitals should be offering care to patients and appear to be in direct conflict with some information that is typically discussed in a prenatal genetic counseling experience. This study is the first of our knowledge to explore the experience of prenatal genetic counselors working in Catholic settings. We learned that many genetic counselors across the regions were able to use their jurisdiction to interpret the religious directives and felt that they minimally impacted patient care. Additionally, while termination is a delicate subject and the procedure is never performed within the Catholic hospitals, patients were generally able to obtain information about termination of an affected pregnancy, if desired. Some counselors found they had to be cautious about how they talked about termination or documented it in their clinic notes, while others were able to completely document the discussion and assist the patient with a referral if needed. Ultimately, what this study shows is that patients are in the forefront of the minds of these genetic counselors. They desire to do what is in the best interest of the patient so that when conflicts do arise, counselors side with the patients, much as their colleagues that work in other settings do.
Appendix A: NSGC and ABGC Recruitment Language

Do you work or have you worked in a prenatal setting? Do you (or have you) worked in a Catholic hospital setting?

My name is Katie Schwarting and I am second year genetic counseling student at Brandeis University. I am currently working on a thesis project entitled “An Exploration of the Art of Prenatal Genetic Counseling in Catholic Hospitals”. The purpose of this project is to understand the experience of a prenatal genetic counselor in a Catholic hospital in light of certain institutional guidelines.

All certified prenatal genetic counselors that are currently working or have worked in a Catholic hospital within the past 5 years are invited to participate.

Participants in this study will complete one telephone interview with the student researcher that will take approximately 40-60 minutes. The interviews will be recorded and transcribed. To protect your privacy, all identifying information from participants will be omitted from the transcribed interviews. All participants who complete an interview will receive a $25 Amazon gift card as compensation for their time.

This study has been reviewed and approved by the Brandeis University IRB.

If you would like to participate in this study, or if you have questions, please contact me, Katie Schwarting at kschwarting@brandeis.edu or 757-334-3683. Also feel free to pass this notice along if you know of another genetic counselor who might be interested/eligible.

If you wish to participate, I will contact you to obtain your informed consent and to schedule a mutually convenient time for an interview.

Thank you!

Katie Schwarting
Graduate Student Researcher
Brandeis University
kschwarting@brandeis.edu

Cassandra Buck, MS, LCGC
Advisor for Genetic Counseling Research
Brandeis University
cbuck@brandeis.edu
Appendix B: Information Sheet

You are invited to participate in a research study being conducted by Katie Schwarting, a genetic counseling Master’s Candidate at Brandeis University. The study is being conducted under the supervision of Cassandra Buck, MS, LCGC.

Please read this info sheet carefully. Participation in this study is voluntary, and we want you to feel comfortable. We encourage you to ask questions if you want more information about any part of the study. You will be asked if you understood all the information in this information sheet, whether you have any questions, and if you voluntarily agree to participate in the study before we begin the interview.

Purpose of the study:
The aim of this study is to learn more about the experience of prenatal genetic counselors who work in Catholic hospitals.

Study Procedures:
If you agree to take part in the study, you will be asked to participate in a recorded phone interview, lasting 40-60 minutes. You will be asked questions about your experience working in a Catholic hospital, the testing options offered in your hospital, the availability of pregnancy terminations, and the challenges and joys of working at a Catholic hospital. If you would like to participate but do not want to be recorded, you may still participate. Notes will be taken in lieu of a recording.

Benefits:
There is no direct benefit to you. We hope in the future, information from this study will help us gain a better understanding of the experiences of prenatal genetic counselors in a Catholic setting.

Risks:
Your participation in this study presents no more than minimal risk. It is possible that talking about your experiences could cause distress. If you become uncomfortable, you can ask the interviewer to skip a question or move on to a different topic. You could also choose to end the interview entirely.

There is always the risk that your information could be accidentally disclosed to people not connected with this study; however, we will do our utmost to secure our information so this does not happen.

Privacy and Confidentiality:
All records containing identifying information, such as names and email addresses, will be kept strictly confidential during the study. All study related documents and materials (including eligibility questionnaires, interview recordings and transcripts) will be deidentified (stripped of your name/identifiers and labeled with a code and kept in a secure online location accessible


only to the principle investigator and student researcher. The key, linking your research code to your identifying information, will be kept in a separate password protected document on the student researcher’s computer with your identifying information. If you are quoted or referred to in any written or oral reports of this study, you will be given an alternate name. You will never be referred to by your name or any other identifying information in any written or oral reports.

The list with identifiers will be deleted after the interviews have been completed and the Amazon gift cards have been sent. All other data collected will be destroyed after the publication of the research findings.

Cost and Compensation:
There will be no cost to you to participate in the study other than the time it takes to conduct this interview.
As a token of our appreciation for your time, we will send you a $25 Amazon gift card upon completion of the interview.

Contact information:
If you have any questions about the study, please contact the student researcher, Katie Schwarting, kschwarting@brandeis.edu. If you are having difficulty reaching Katie Schwarting, or if you encounter problems related to the study, you may contact the principle investigator for this project, Cassandra Buck, cbuck@brandeis.edu.

If you have questions about your rights as a research study subject, contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8133.
Appendix C: Interview Guide

Review of Information Sheet
Do you have any questions about the information sheet?
Do you agree to participate?
Do you agree to be recorded?

Introductory/Demographic questions:
1. How many years have you been practicing as a genetic counselor?
2. How many years have you worked as a prenatal genetic counselor?
3. How many years have you worked at a Catholic hospital?
4. Have you always worked at a Catholic hospital?
   - If no, what factors went into you deciding to work in a Catholic hospital?
5. Are there other competing hospitals or MFM practices in your area?
6. What region do you practice in?

Session questions
7. Tell me about a typical session you might have with a patient
   - What are the testing options you typically offer?
   - Screening? Diagnostic?
8. What options do you typically discuss with patients/couples that have received a positive result?
   - Diagnostic testing? Referrals to specialists to discuss management? Termination of the pregnancy?
   - Do you feel that you have the freedom to provide your patients with all of the relevant information?
9. Do you ever discuss the option of termination of pregnancy during a session?
   - If no, why not? Do your institutional guidelines prevent you from discussing termination of pregnancy?
   - If yes, for what indications do you discuss this option?
   - Does your hospital perform terminations?
   - How do you address a patient who asks about termination?
   - Do you ever refer patients who are carrying a pregnancy affected with a genetic condition to another hospital?
     - If yes, why?
     - If no, why not?
10. Do you feel that your hospital’s institutional guidelines regarding termination of pregnancy affect how you counsel patients?
    - If yes, what kind of effect do these guidelines have on your sessions?
    - Do you ever feel conflicted between your duties as a genetic counselor to inform your patients of all of their options and your institution’s rules?
    - If you worked in a non-Catholic hospital previously, how do the guidelines at your current hospital compare to those in the other hospitals you have worked?
11. What is the most rewarding part of working in a Catholic hospital as a prenatal genetic counselor?
12. What is the most frustrating part of working in a Catholic hospital as a prenatal genetic counselor?
13. Is there anything else you would like to add?
References


de Vogue, A., Kopan, T., Berman, D. (June 2016). Supreme Court strikes down Texas Abortion access law. *CNN.*