The Psychosocial Impact of Termination of Pregnancy for Fetal Anomaly on the Male Partner

Master's Thesis

Presented to

The Faculty of the Genetic Counseling Program
Graduate School of Arts and Sciences
Brandeis University
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In Partial Fulfillment of the Requirements for

Master's Degree

by
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ABSTRACT

The Psychosocial Impact of Termination of Pregnancy for Fetal Anomaly on the Male Partner

A thesis presented to the Genetic Counseling Program

Graduate School of Arts and Sciences
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Waltham, MA

By Jennifer Desrochers

There is a wealth of knowledge in the literature about the effect of termination of pregnancy (TOP) for fetal anomaly on women. However, little is known about the psychosocial impact of this traumatic loss on male partners. The purpose of this study was to explore the thoughts and feelings of fathers throughout the experience including the initial diagnosis and the decision-making process, as well as the journey of grieving and coping. We conducted semi-structured qualitative interviews either face-to-face or by telephone with seven men whose partners had undergone TOP for fetal anomaly at least four months prior to the interview. There were five main categories of discussion during the interviews: (1) Initial Reaction, (2) The Decision-Making Process, (3) Grief Responses, (4) Coping Mechanisms and Strategies, and (5) Advice for Genetic Counselors and Other Men. We found that the decision-making process was one of the most difficult aspects of the experience for the fathers. They agonized over the choice because none of their options felt right. Among other factors, they primarily took the impact on family life into account when making the decision. Once they decided on TOP,
the fathers struggled with how to tell other people, seeing other pregnant women and children, and being supportive of their spouses. Overall, our respondents reported that the loss did not have a negative impact on their relationship with their partner. The fathers’ main coping strategy was to internalize their feelings, although they expressed the need for a variety of coping strategies. Genetic counselors can provide additional support by making male partners aware of resources including therapists, support groups, and the contact information for men who have had similar experiences.
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INTRODUCTION

Couples face a long and difficult journey after receiving a prenatal diagnosis of a birth defect or chromosome abnormality. The emotional turmoil associated with receiving a diagnosis, making the decision whether or not to terminate the pregnancy, and the resulting psychosocial effects of that decision for women has been researched and reported extensively (Korenromp et al, 2005; Korenromp et al, 2007, *AJOG*; Korenromp et al, 2007, *Prenat Diag*; McCoyd, 2007; Sandelowski & Barroso, 2005; Statham et al, 2000). However, an area of knowledge in which the literature is lacking is how termination of pregnancy for fetal anomaly affects the male partner. Ultimately, by understanding this experience from the male partner’s point of view, from receiving the diagnosis to coping with the outcome, healthcare providers can learn how to better support couples facing a diagnosis of fetal anomaly.

From the beginning, women tend to assume that their pregnancy is developing normally (Lalor et al, 2009). In the majority of cases, this assumption is accurate and the pregnancy results in a healthy baby. When a fetal anomaly is diagnosed parents may react with a variety of feelings, especially shock from the unexpected news. Once the shock of receiving a diagnosis has passed, the next step of the grieving process is to ‘gain meaning.’ Gaining meaning results from learning more information about the diagnosis and what continuing or terminating the pregnancy may mean for the family.
There are many important factors that couples take into account when determining the best course of action for them. Couples often contemplate the social implications of having a child with disabilities (McCoyd, 2008). While some parents have a positive outlook or expectation about the future social functioning of a child with physical or intellectual disabilities, some parents may feel anxious about the possibility that their child might face exclusion and isolation among their typically developing peers.

Having a child with disabilities also has many implications in family functioning (Sandelowski & Barroso, 2005; McCoyd, 2008). Many women report concerns about the financial burden and other resource limitations associated with physician visits, therapy, hospital stays, etc. Other factors women considered were how many children they had and possible effects on both sibling relationships and their relationship with their partner or husband.

Finally, many conflicting personal feelings about perceived ability to parent a child with disabilities play an important role in the decision to continue or terminate a pregnancy (Sandelowski & Barroso, 2005; Korenromp et al, 2007, AJOG; McCoyd, 2008). Likewise, guilt, doubt, and regret all play an integral part in the decision-making process. Women report being influenced by both the guilt of knowing their child will suffer and the guilt of choosing termination of pregnancy. They may express regret and doubt about their final decision to terminate the pregnancy.

In addition to these social, familial, and personal implications, one of the most important factors influencing the decision-making process is perceived partner support (Korenromp et al, 2006; Korenromp et al, AJOG, 2007). This is particularly relevant to
future research regarding the role that male partners play in this process. Many studies have uncovered information about how partners interact when engaged in the decision-making process. When assessing women’s motivations behind choosing to terminate a pregnancy after a diagnosis of Down syndrome, 55% of women reported that the burden [was] too heavy for [their] relationship (Korenromp et al, 2007, *AJOG*).’ Another 11% of women reported that they ‘acquiesced to [the] wish of [their] partner to terminate.’ Additionally, of the 1 in 5 women that reported a high level of doubt about their decision to terminate the pregnancy, 38% of them reported that their increased doubt was due to disagreement with their partner. Men often defer to women to make the final decision about whether to continue or terminate the pregnancy because they view it as the woman’s choice (Sandelowski & Barroso, 2005). While the final decision may be regarded as the woman’s responsibility, other themes from the study implied that feeling justified in their choice seems to result from a combined effort of the couple to reach a mutual decision.

The psychological impact of a pregnancy termination is thought to be more severe and prolonged for women than for men (Sandelowski & Barroso, 2005; Korenromp et al, 2005, 1226-1233). This is at least partly a consequence of bonding that results from experiencing fetal movements before the termination. The physical connection between mother and child is a constant presence. The mother has likely seen ultrasound pictures, heard the baby’s heartbeat, and felt the fetal movements. She has daily reminders of pregnancy such as changes in her diet and body. These changes continue even after the termination such as the expression of milk post termination, which can be very painful reminders of the loss of a wanted baby.
The risk factors for an adverse psychological outcome in the short term include poor perceived partner support, religiosity, and advanced gestational age at diagnosis (Korenromp et al, 2009). These factors were found to still be significant four months post-termination of pregnancy. While gestational age did not appear to heavily influence the decision-making process, it has been linked to a poor psychological outcome in the short term (Davies et al, 2005). Women that chose termination of pregnancy after a diagnosis in the second trimester were significantly more distressed six weeks after the termination than women who received a diagnosis in the first trimester of pregnancy. The difference between the two groups diminished by six months post-termination.

The risk factors for an adverse psychological outcome in the long term continue to be poor perceived partner support and advanced gestational age (Korenromp et al, 2005, 253-260). Other factors that emerge in the long term are a low level of education and the chance of viability. Having a chance of viability increases both the level of doubt about the decision to terminate the pregnancy as well as the level of grief. Having children at the time of the termination of pregnancy is associated with a positive psychosocial outcome (Korenromp et al, 2005, 1226-1233).

The male partner experiences the process of receiving a diagnosis, making a decision about termination of the pregnancy, and grieving the loss of the pregnancy alongside their female counterparts. They react differently to the grief, but they experience grief nonetheless. Studies have shown that differences in expression of grief between genders may be attributed in part to socially guided gender roles (Doka & Martin, 2010). From an early age, men are discouraged from expressing their feelings or
making outward displays of emotion (Statham et al, 2000; McCoyd, 2007). Their role is to provide for their family and remain strong in times of distress. In short, these gender roles dictate that men react stoically to grievous events. However, a stoic demeanor can often be translated as being uncaring and unaffected. While men are encouraged to hold in their emotions, they are also berated for not acting in a more sensitive manner. This miscommunication can undermine and weaken the relationship between couples. Great care should be taken by healthcare providers to point out this difference of expression and to ensure that each member of the couple is receiving needed support.

Although many common risk factors associated with an adverse psychological outcome, such as having poor perceived partner support, a higher gestational age, a high level of decisional doubt, high perceived pressure, and being religious, are the same for both men and women, there are factors that put men at greater psychological risk than women (Korenromp et al, 2007, *Prenat Diag*). In the short term those factors include: undergoing a medical induction of labor instead of dilation and evacuation or selective reduction as the method of termination. In the long term, terminating a pregnancy for an anomaly that is compatible with life was the only significant factor associated with adverse psychological outcome (Korenromp et al, 2005, 1226-1233). The authors did not speculate about why these factors impact the father’s experiences and no follow-up studies have been done for further exploration.

While the existing data suggests that men have an emotional role in the process of choosing termination of pregnancy for fetal anomaly, the literature is still limited in the amount of data surrounding this topic. Understanding communication of grief and how that experience differs between men and women is essential for healthcare
providers who are trying to support both members of the couple. By recognizing the signals that the male partner in the couple is becoming distressed, proper referrals can be made and support can be offered to help a father process his grief. Awareness of the alternative expressions of grief can help a genetic counselor facilitate a delicate discussion between male and female partners who may require different approaches and supports as they work through their loss.
METHODS

Sampling Methods

We conducted qualitative face-to-face and telephone interviews with men whose partners have previously elected to end a pregnancy as a result of receiving a prenatal diagnosis of fetal anomaly. Eligible participants were males over 18 years of age, who experienced a pregnancy loss at least four months prior to the interview. We recruited seven participants from the greater Boston area through the private practices of a local certified genetic counselor and thanatologist as well as a licensed social worker. They relayed information about the study to male clients who had successfully ended their therapeutic relationships with them (Appendix A) and obtained permission to share their contact information with us. We then contacted the potential participants, confirmed eligibility, and scheduled interviews. We offered the participants a $25 gift card as a gesture of our appreciation for their time.

Interview Design

We designed a semi-structured interview guide to facilitate a conversation about the participant’s experience with termination of pregnancy due to a fetal anomaly (Appendix D). The questions were designed to qualitatively explore how fathers experience and process grief after the loss of a pregnancy and if they perceive differences in the grieving process between themselves and their partners. The
interview guide also explores in what ways the experience has affected the father’s relationship with his partner.

Data Collection

Before proceeding with interviews, we obtained additional demographic information (Appendix B) including age, occupation, relationship status, number of children, and home state. We also obtained informed consent (Appendix C). The audiotaped interviews lasted approximately 50-60 minutes and were conducted either face-to-face or by telephone. We used a semi-structured interview guide with open-ended interview questions. This approach allowed participants to respond freely and without interruption. We allowed the use of additional questions and responses as well as flexibility in the order of our questions to allow the conversation to progress naturally. However, the overall content of each interview was consistent.

Several measures were taken to ensure confidentiality and privacy for the participants. All documents containing identifying information were kept in either a password-protected database or a locked filing cabinet in the Genetic Counseling Program’s space to which only the student researcher and the Program faculty have access. The informed consent forms will also be kept in this filing cabinet for five years. The participants’ names and demographic information were not linked to the interview transcripts in any way and transcripts, field notes, and memos were labeled with numbers instead of names. All data including transcripts, recordings, field notes and any other related files were destroyed once the study was completed.
Data Analysis

We sent the audiotaped recordings of the interviews to a confidential transcriptionist to be transcribed. The transcripts were imported into the qualitative analysis software, ATLAS.ti (version 5.0) for analysis. We created codes that represented ideas, thoughts, and feelings expressed by the participants and assigned them to corresponding phrases in the transcripts. We organized the codes by frequency and extracted the most commonly mentioned ideas, thoughts, and feelings as major themes. These themes were thought to best represent the participants’ common experience.
RESULTS

Demographics

Seven men between the ages of 33 and 52 years (Average 38.7 years) participated in the research study. All seven participants live in the greater Boston area and are currently married to their partners with whom they experienced the termination of pregnancy (TOP). The range of time that had elapsed since the TOP was between 8 months and 3 years (Average 21 months). The women were between 20 and 32 weeks gestation (Avg. 23.1 weeks ±4.3) at the time of TOP. Two of those pregnancies were beyond 24 weeks, the gestational age at which it is legal in Massachusetts to undergo a TOP. These two couples travelled outside of the state to obtain the termination. The fetal anomalies affecting the pregnancies included: trisomy 18, small kidneys, polycystic kidney disease (PKD), tetralogy of fallot, brain malformation, trisomy 21 with a complex heart defect, and spina bifida. Table 1 summarizes the information above as well as the number of children the couple had before the TOP and the number of children they had after.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (Years)</th>
<th>Gestation at TOP (Weeks)</th>
<th>Fetal Anomaly</th>
<th>Time Elapsed</th>
<th># of Children Before</th>
<th># of Children After</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>52</td>
<td>20</td>
<td>Trisomy 18</td>
<td>2 Years</td>
<td>0</td>
<td>1 (adopted)</td>
</tr>
<tr>
<td>2</td>
<td>34</td>
<td>32</td>
<td>Small Kidneys</td>
<td>3 Years</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>37</td>
<td>25</td>
<td>PKD</td>
<td>10 Months</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>33</td>
<td>23</td>
<td>Tetralogy of Fallot</td>
<td>1.5 Years</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>48</td>
<td>21</td>
<td>Brain Malformation</td>
<td>1.5 Years</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>34</td>
<td>20</td>
<td>Trisomy 21, Complex Heart Defect</td>
<td>8 Months</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>33</td>
<td>21</td>
<td>Spina Bifida</td>
<td>2.5 Years</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 1. Summary of participant demographics.

Themes

The interview questions were designed around five main areas of discussion: (1) Initial Reaction, (2) The Decision-Making Process, (3) Grief Responses, (4) Coping Mechanisms and Strategies, and (5) Advice for Genetic Counselors and Other Men. By categorizing the codes used for analysis under those areas of discussion and examining the frequency of comments, we extracted seven main themes and several sub-themes from the data representing the chronology of the participants’ experience. Figure 1 summarizes the themes and sub-themes expressed by interviewees.
Figure 1. Summary of 5 main areas of discussion, corresponding themes and sub-themes.
Initial Reaction

Theme: Shock and Devastation

The initial reaction to the diagnosis of a fetal anomaly was one of shock and devastation for many of the participants; the grieving process began with the loss of a normal pregnancy. One participant recollected these initial feelings by saying,

“We, I think there was kind of this, I guess like a lot of expectant parents, there was a sense of kind of growing delight, a sense that somehow we were connected to this child. We had started talking to her, and I would put my head on my wife’s belly and sing, and we would talk to the child directly through...Who knows what she heard, what she perceived, but there was a lot of joy in that process of ‘Oh my God, this is really going to happen for us.’ After one...I think it was after the first trimester and we felt like ‘Wow, we made it through the hardest time. This is probably going to really happen.’ And it’s kind of hard to describe that, just the feelings themselves, and looking back I’d say a tremendous sense of loss.”

Two other participants mentioned similar feelings of shock after the initial diagnosis. One said, “You never think that something like that is going to happen to you, and then it does, and you just feel like you’re in the clouds for a while.” The other father admitted, “Like I said I was falsely hoping that, ‘Yeah, we’re going to be okay.’ And the slumber would lift and then it just kind of all crashed.”

The Decision-Making Process

Theme: Discomfort with Options

Four out of the seven participants commented that they felt that the decision was difficult to make because neither option felt like the ‘right’ thing to do. One participant expressed the pain of making this kind of decision by saying,
“I had to tell myself that it stinks. That’s it. That’s all I could know. No matter how many ways I beat myself up over it, it’s not going to change the situation. I either have to accept the situation or I’m just going to be a mess and I’m not going to be able to be there to support my family and things like that.”

Another participant said,

“There’s just no way to make it easy. That’s the thing. It’s clearly one situation where there is absolutely no way you could make lemonade out of lemons. It’s just very hard. My job, I pride myself on being a great problem solver, but there was no answer to this.”

It was clear from their statements that it was difficult to fathom having to make such a heartbreaking choice.

*Theme: Most Emotional Time*

When asked what the most difficult aspect of the experience was, there were common responses among all the participants. Three out of the seven participants answered that making the decision was the most difficult part. One participant said,

“And that’s really hard to deal with in being so excited to have a child and having it ripped away from you, the idea of having a baby that’s healthy or that can function. It’s just...it was crushing. That was probably the hardest part of dealing with that actual decision of termination was...it’s huge. It was huge.”

Both of the participants with pregnancies affected with lethal anomalies said that the process of actually going through the termination was the most difficult part of the experience. One participant expressed this by saying,
“And I can remember at [the hospital] obviously they go in to put the baby to sleep before you actually have it. And I remember her just looking at me as they were doing it with a tear in her eye, and it was probably the most difficult thing I’ve ever been through. I can’t tell you how much I love my wife. Just looking at that expression on her face when they were doing that to the baby. It’s kinda choking me up a little bit right now talking about it.”

Making the decision seemed to be associated with a high level of emotion. Only two out of the seven participants said explicitly that they felt they had made the right decision. Interestingly, these were not the fathers with lethal anomalies. One participant said, “We came to an agreement about that and that was the right decision. I feel good about the decision. I feel like we did the right thing for our family. That kind of makes me sleep a little better.” This was not the most common response, but it did comprise approximately 29% of the sample. It would be interesting to examine these responses in the context of a larger sample size since the decision making process was identified as a very emotional time for these participants.

All seven participants reported struggling with the viability of the anomaly during the decision-making process. They all took into account the personal impact of the type and severity of disability their child would suffer if they decided to carry the pregnancy to term. This seemed to be a major factor in the decision-making process. One participant said,

“There is a black and white consequence of the choice we made, the termination, but what happens after that is gray. We don’t know how we’re going to react. We don’t know how it’s going to affect our family. But at the same time we don’t know what the spectrum is going to be...We wanted someone to just tell us, ‘The baby will not survive more than an hour.’ Or something like that. ‘This is so severe that your only choice is termination.’ No one -- and rightfully so, no one could tell us that was our only choice.”
On the surface, not knowing how severely disabled their child might be impacted the difficulty of the decision-making process. However, on a deeper level, considering viability seemed to be linked to guilt and shame that the couple felt for choosing to terminate a wanted pregnancy. The fathers expressed not wanting to make such a horrible decision. Having someone tell them what choice to make may have taken the guilt off of their shoulders.

**Grief Responses**

*Theme: External Loss Issues (Society)*

A common theme that came up in the interviews many times was struggling with how to share the news that their wife is no longer pregnant. Six out of the seven fathers mentioned that they took great care in deciding who to tell and how much information to share for fear that they would be judged for the decision they made. One participant described this feeling by saying,

> “And I do remember first of all a sense of not being able to tell very many people and that there was a real sense of loneliness about that. A few close friends knew. One of my family members knew.”

Another participant explained it by saying,

> “So we just had a few people that we had trusted and confided in, and I think the hard part in the beginning, too, is you have got to go out and communicate to everybody what happened without really telling them what happened.”

The fathers in this study clearly struggled with feeling obligated to provide an explanation for the pregnancy loss, whether it was for friends, family, or co-workers. It put them in a vulnerable position to share a deeply personal experience with those who knew about the pregnancy.
Another factor that brought their grief to the surface was seeing pregnant women or babies out in public. Six out of the seven participants mentioned feeling upset by this. Other women at the abortion clinic having elective terminations, other pregnant friends or family members, and seeing people with children elicited strong emotions in both the participants and their wives. One participant said, “The most challenging I would say is reliving it through stories and seeing your friends having children. You always think, ‘Why is it me?’ Being reminded of it was the most challenging.”

In response to seeing women at the abortion clinic another participant said,

“Seeing all them, it was mainly young women... Just feeling like, ‘Wow... I wish we could have traded.’ That we could have had that healthy baby and we would have kept it. But we were there in a way for a very different reason than they were. That we really wanted to pregnant and we wanted a healthy baby and that’s not what we had.”

Another father described what it was like to see children after the termination:

“So I just, I kind of kept it all inside and it was...I’d cry a lot if I saw something. Kids, you know, it still affected me emotionally. But talking, I didn’t do a lot of that.” Not only was it difficult for their partners, it was also difficult for the fathers to be reminded of the loss. Learning how to go back out into the world and cope with daily interactions was a particularly challenging piece of their journey through the grief process.

*Theme: Internal Loss Issues (Family)*

All seven participants spent time speaking about what this experience was like for their spouses. Each participant asserted that the experience was very different for their partners because they were carrying the baby. Their partners’ bodies went through the trauma of losing a connection with the baby that the fathers were unable to feel. The fathers still grieved, but in a different way than their spouses. One participant
described it by saying, “I remember thinking a number of times, 'She had this person inside of her, so naturally this is going to be a harder process for her.'”

Six of the participants mentioned specifically that they felt that their partners had a harder time or that the loss was more painful for them. Another six of the participants also mentioned that they felt one of their roles was to be as supportive of their partners as possible given the differences in the grieving process. They each acknowledged their own sadness and grief over the loss of the pregnancy, but also expressed the pain they felt for their wives’ loss. For example, one father said,

“I think there is this temptation to say, ‘It’s her body. The baby is inside of her. She’s going through a harder time.’ All that was true, but I think there was sometimes a temptation to say, ‘This is harder on her. And I need to put aside what I’m going through now and be the one to be supportive of her.’ And I think she and I are both aware that the various emotional difficulties, losses that we have gone through, that kind of whoever is hurting the worst, the other person tends to put their things aside. But I think there is also recognition that I couldn’t always do that. That it was okay to be the one who was hurting sometimes, and it was okay to be the one who was in tears…”

Another participant recalled feeling guilty for going back to work instead of staying home with his wife:

“I felt guilty going back to work when my wife was taking time off to grieve. I felt, I did feel guilty. I always wondered if she’d get mad because maybe she thinks I don’t care because I’m already doing the things that need to be done while perhaps she’s still to herself and dealing with what she has to deal with.”

The fathers wanted to be supportive of their wives because they felt it was a more difficult experience for them. This caused the fathers to struggle with coping and moving on themselves.
While each partner was experiencing his or her own personal grief response, their relationship was affected as a couple going through the traumatic event together. All seven participants are still married to their partners with whom they experienced the TOP. Four participants said that they felt their relationship was stronger after the experience. One participant mentioned feeling very secure in his relationship. He said, “...just knowing that [my wife] and I were going through it together. That we were more or less on the same page, that neither of us was going anywhere, that we weren’t going to let it break us apart...” Another participant described his relationship with his wife:

“But now we’re bonded by a lot of good things and bad things that make us that much stronger. We’ve been through so much together that most people never have to go through hopefully. When you think about that, and you’re pissed off at each other, and you just realize, you look at each other and go, ‘Okay, we’re mad at each other, but whatever. This is nothing. Let’s get through it.’”

Only one participant said that the relationship was suffering after the experience. Overall, the experience did not negatively impact the relationship for the majority of the participants.

Coping Mechanisms and Strategies

Theme: Diversity in Coping Styles

Each participant used a wide variety of coping mechanisms and strategies. Table 2 summarizes what kinds of strategies the participants used and how many of the participants mentioned each strategy.
<table>
<thead>
<tr>
<th>Strategy</th>
<th># of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talk with Wife</td>
<td>7/7</td>
</tr>
<tr>
<td>Internalize Feelings</td>
<td>6/7</td>
</tr>
<tr>
<td>Seek Therapy/Support Group</td>
<td>6/7</td>
</tr>
<tr>
<td>Talk to Friends</td>
<td>5/7</td>
</tr>
<tr>
<td>Talk to Family Members</td>
<td>5/7</td>
</tr>
<tr>
<td>Seek Information</td>
<td>5/7</td>
</tr>
<tr>
<td>Initial Denial</td>
<td>5/7</td>
</tr>
<tr>
<td>Focus on Future Children</td>
<td>4/7</td>
</tr>
<tr>
<td>Focus on Existing Children</td>
<td>4/7</td>
</tr>
<tr>
<td>Problem-Solving</td>
<td>3/7</td>
</tr>
<tr>
<td>Seek Religious/Spiritual Support</td>
<td>3/7</td>
</tr>
<tr>
<td>Talk to Co-Workers</td>
<td>3/7</td>
</tr>
<tr>
<td>Passage of Time</td>
<td>2/7</td>
</tr>
<tr>
<td>Have a Memorial</td>
<td>2/7</td>
</tr>
<tr>
<td>Seek Support from Medical Staff</td>
<td>2/7</td>
</tr>
<tr>
<td>Take a Vacation Alone with Wife</td>
<td>2/7</td>
</tr>
<tr>
<td>Visit a Memorial</td>
<td>2/7</td>
</tr>
<tr>
<td>Spend Time with the Baby</td>
<td>2/7</td>
</tr>
</tbody>
</table>

Table 2. List of coping mechanisms/strategies in order of most-mentioned to least-mentioned.

It was moving to see how resourceful and courageous these men were in facing such a tremendous loss. They each chose an array of coping strategies to overcome the sense of grief and sadness they felt after the loss of the pregnancy. Interestingly, these coping mechanisms are quite similar to those reportedly used by women.

*Theme: Internalize Feelings*

There were many coping mechanisms described by the interviewees, however one of the main coping mechanisms described was to internalize their feelings and try to move on from the event. Six out of the seven participants mentioned putting the past behind them and trying to focus on the future. One participant said, “I dealt with it quietly. At work I felt, just kinda off. That’s all I can describe.”

Other participants described this by saying,
“I’ve just been trying to put it behind me. That’s how I’ve been managing to cope... Just try and forget about it. Obviously you never forget about it. It’s not something you’ll ever forget about. It’s just something you learn to live with. But I have just tried to put it behind me.”

“My wife is more expressive and wants to go back and think about it every time and if you asked me the date I couldn’t even tell you the date and my wife would be horrified about that. She would be like, ‘How come? Let’s celebrate. Let’s go on a walk,’ something like that, whereas I don’t ever want to think about it again. I don’t know if that’s male or female thing or it’s just me but anyway, I just try to get just the positive. What works for me I guess... And I just thought the whole thing sucked and we were reliving it but I didn’t tell her that but here we are with my best friends and their wives and we’re doing a picnic and it was so uncomfortable. It reminded me of a funeral or a memorial.”

Another interesting finding was that two of the seven participants commented that they had not thought about the experience in preparation for the interview. One participant said, “It’s funny, knowing this was coming up, I still didn’t think things through very carefully.” Pushing their thoughts about this traumatic experience under the surface and focusing on the future seemed to be a less painful coping strategy than talking about and reliving the experience.

**Advice for Genetic Counselors and Other Men**

**Theme: Importance of Support**

When I asked the participants what they would like genetic counselors to know in order to better support fathers going through this difficult experience, many of them explained what they thought their genetic counselor’s role was. Six out of the seven participants thought that the genetic counselor should take care to be very supportive, especially during the decision-making process. Additionally, five participants either received or would have liked to receive a list of resources they could access if they
needed further support. Finally, three of the participants mentioned that they found it very helpful for their genetic counselor to coordinate their care by setting up appointments for them. One participant described the support they felt from their genetic counselor:

“I thought [our genetic counselor] did a really nice job of comforting us through the process, and listening, and asking questions and providing helpful, thoughtful resources for us. But listening, and checking in with us, being compassionate. Asking, when you say something to the effect of, when you hear someone...I think people in general want to be, I think people want to be understood. And they want to be, they want people to feel like, feel like they understand, or at least help them cope with it a little bit, yet not be over the top with it.”

Another participant described wishing they had a list of resources:

“But I think having resources available, maybe whatever the person decides to do. Like having somebody like [our therapist] in their back pocket...We had to search quite a bit to find [our therapist]. It would have been nice for our genetic counselor to have a list of resources we could have turned to immediately.”

Finally, another participant summarized what he thought the most important roles genetic counselors could fulfill by saying,

“I think there are two things that a genetic counselor could do for a father. Number one, make them feel at peace with whatever decision it is that they choose to make, and to facilitate, help them make that decision. And then number two, to ensure that they are highly supportive of their wives, because it’s different for the mother than it is for the father.”

More than providing information about the anomaly and recurrence risks, the fathers felt the support and resources their genetic counselors provided was their most helpful role.
Two participants suggested seeking therapy or support groups as a way for other men to cope with a pregnancy loss. One participant mentioned wishing there was an online support group for men. He said, “My first though is to say that one of the things that really made a difference for my wife was having that... website. And that we were not aware of a similar way for men to connect.”

However, another participant thought that men were not likely to seek out or wish to speak with other men having gone through a similar experience. He said, “I would never talk to a guy...Not that I wouldn’t talk to somebody if [our genetic counselor] was like, ‘Could you talk to a guy that went through this?’ Sure. But I don’t know if that guy’s going to want to come to me. I just don’t think we’re wired that way.” Only one participant mentioned that men should not try to be stoic. The participants generally embraced the role of being the ‘strong one’ and not wanting to seek additional support.
DISCUSSION

It is heartbreaking for a wanted pregnancy to be prenatally diagnosed with a fetal anomaly. This devastating loss is traumatic not only for the mothers, but also for the fathers. We found that the fathers had a range of grief responses as profound and far-reaching as their partners.

The idea of how to tell other people about their experience came up often in the interviews. Fathers struggled with deciding in whom they could confide and how much information they were willing to disclose. A confounding factor is how many people already knew their wife was pregnant. The fathers were concerned about being judged for their decision and so greatly limited the number of people with whom they shared the full details of the experience. One father in particular felt “a real sense of loneliness” with this problem and may have benefitted from additional support surrounding this matter. The anguish of disclosing details of the experience may result in part from having to relive the experience during every retelling of the story. A coping mechanism such as internalizing the experience, one of the most talked about coping strategies by the interviewees, cannot be used if one is constantly being asked about what happened. For a majority of these couples the pregnancy has been announced to family and friends and if for any reason their pregnancy does not continue to term, the couple feels responsible for giving an explanation thereby reopening the story and exposing their feeling of loss. It is upsetting for women to explain what happened to the pregnancy, but these results show that it is also quite difficult for the fathers.
When discussing the depth of their grief, another topic interviewees frequently mentioned was what the experience was like for their spouses. The overall sentiment expressed by the fathers was that they perceived that the loss was much more difficult for their partners because they had a stronger connection to the baby. The fathers acknowledged that the pregnancy was more abstract for them because they were not carrying the baby. Therefore, they felt like their main role was to be as supportive as possible of their wives. Although they accepted this role without resentment, they struggled with being continuously supportive throughout their own grieving process. Because they commonly coped by internalizing their feelings and trying to look to the future, it may have been difficult to continue to revisit the loss while their wives were still struggling with the past. One father described feeling guilty that he was going back to work and trying to move on while his wife needed more time. At times, the fathers may have felt like they were unable to focus on their own coping strategies because they felt the instinct to focus on their wives. One father described this struggle by saying,

“But I think it might have been helpful to know that... [my wife] was going to need a lot of sources of support and that all of her support couldn’t come from me. I knew that, but there were still times where I felt like ‘I’m letting her down. I don’t know what to say.’ Or, ‘I’m tired of this. Here we are six months later and it’s still coming up.’”

Two of the fathers said when they found themselves struggling to be supportive because they were trying to cope with their own grief their wives were able to reciprocate the support. In this way these couples were able to trade roles so that both partners were supportive and felt supported. Another study found this to be true when assessing psychological morbidity in couples that have undergone TOP for fetal
anomaly (Korenromp et al, 2005, 1226-1233). When one partner scored in the pathological range for a particular measure such as grief, anxiety or depression, the other partner never had a pathological score concurrently.

Being able to successfully reciprocate support may be one of the reasons that many of the fathers felt that their relationship was stronger after the experience. There seemed to be something unique about providing mutual support that makes the relationship more resilient. We know that a traumatic experience can damage a relationship (Statham et al, 2000; McCoyd, 2007), but 71% of the participants felt that their relationship was stronger and 100% are still married to their partner. Grieving this experience together did not seem to have an overall negative impact on the relationship. On the contrary, something about the way they communicated with each other throughout the grieving process has strengthened their relationships. This idea of reciprocal support seems to be one piece of that puzzle.

Overall it is interesting that while there may be the assumption that the grieving process is much different for the fathers, their responses indicate that there are many similarities. While their initial coping strategies may be different, the fathers were still devastated by the diagnosis, struggled with sharing the news with others, felt saddened when seeing other pregnant women and children, and were still greatly affected by the loss at the time of our interview. These are all feelings expected from the mothers, but it is easy to overlook that the fathers have the same thoughts and feelings.

Not dissimilar from their partners, the fathers in this study had a myriad of initial reactions to the diagnosis including shock, disbelief, sadness, and feeling overwhelmed. The expectations surrounding ultrasound add intensity to these feelings
(Sandelowski & Barroso, 2005; McCoyd, 2007; Lalor et al, 2009). One father said, “...and then they just break the news to you. So at week 20 we go in there and I was like, ‘I was expecting to learn the sex of the baby.’” Instead of viewing the ultrasound as a way to diagnose an anomaly, couples commonly think about it as a way to bond with the baby. Ultrasound is used to hear the fetal heartbeat, determine the gender, and take pictures to show friends and family. As we have seen both in the literature and this study, a long journey of grieving and learning how to cope with this tremendous loss begins with the diagnosis.

Following the diagnosis, families must decide whether or not to terminate the pregnancy. Many factors come into play during the decision-making process. The fathers in this case focused on explaining not only how this decision would affect the family, but also on how much suffering the child could expect based on the severity of the diagnosis. Each father made some mention of the viability of the anomaly. However, whether or not the anomaly was lethal did not seem to factor into how difficult the decision was to make. The two participants who described lethal anomalies did not indicate that this was an easy decision because of the severity of the anomaly. Furthermore, the two fathers that said specifically that they felt they made the “right” decision were not those with lethal anomalies.

Given these findings, it seems that the amount of difficulty one has with making the decision whether or not to terminate a pregnancy is not correlated with the actual situation, but is due instead to personal factors and the impact the experience may have on the family. Personal coping strategies and culture may play a bigger role in how difficult the decision-making process is as opposed to the severity of the anomaly or
gestational age. The fathers in this study mentioned how important this decision was for family functioning whether or not the child survived if they chose to continue the pregnancy. One father expressed this by saying, “As we went through the process, it went from ‘Okay, we need to deal with this’ to ‘I don’t think we can deal with this and we’re going to have to make some tough decisions here for the sake of the family and the baby.”

There were a vast number of ways in which the fathers coped with the decision to terminate the pregnancy. One of the main ways the fathers said they were coping was by internalizing their feelings. They did not want to focus on the past and relive the experience by talking about it, continuing to go to therapy, or having a ceremony on the anniversary of the termination. Their sadness was obvious as they recounted the tragedy and became emotional during particularly profound moments of the interview. The experience seemed to be so difficult to think about that two of the participants did not think about the experience before our meeting. Instead, after the loss they focused on what needed to be done to keep the household functioning, taking care of their existing children, and going back to work among other things. For individuals using this coping strategy, talk therapy may not be the best way to facilitate the grieving process. They still need support, but perhaps through other activities such as getting together with a group of men with similar experiences for a game or a night out. Some of the fathers admitted that they did not feel therapy was helpful for them, but it was helpful for their partners and therefore them as a couple. It was exceedingly difficult for them to acknowledge the benefits they received from therapy. However, the support they did
receive seemed to be helpful in bringing them closer to their spouses and allowing them to share their experiences and move on.

Internalizing feelings tends to be viewed as an unhealthy or negative way of coping, but this strategy seems to represent what the fathers in this study were seeking to some degree. However, they did express interest in being connected to other men with similar experiences. Although not within the scope of this study, it would be interesting to explore other ways for fathers to obtain support besides a traditional support group. Simply having the opportunity to socialize with couples or individuals with similar experiences may be a helpful way to support those who prefer to internalize their feelings. Feeling connected to the outside world and being social can help bring normalcy back to every day life and keep feelings of loneliness and isolation at bay.

In terms of receiving support, the participants had very specific ideas of what they felt their genetic counselors’ role was. They viewed their genetic counselor as a facilitator to the decision-making process and a source of support for whichever option the couple chooses. It seemed that having a list of resources whether or not they request it would be useful. They mentioned wanting access to a list of support groups, therapists, and the names of other men who had been through similar experiences. They seemed reluctant to use these resources themselves, but they thought it was helpful for their genetic counselor to map out where and how to get support if they decided they needed it. This was exemplified by the father who said that he would talk to another man going through a similar experience but that he did not think that he would seek out a man to talk to.
In addition to giving advice to genetic counselors, I was struck by the advice these fathers would give to others. Although all seven participants sought therapy, only two said specifically that they would tell others to seek therapy. Also, only one father said that other fathers should not try and be the ‘strong one.’ It may not be helpful for genetic counselors to show support by urging the fathers to seek therapy and to ask for help instead of being stoic. These are roles that fathers seem to have embraced, so it may alienate them by asking them to use coping strategies that do not seem intuitive or natural for them. However, the results from this study shows that men feel the loss of a wanted pregnancy as deeply as their partners and have benefited from receiving therapy or other forms of support after this traumatic experience. Genetic counselors would be remiss to neglect pointing this out and offering them additional support.

Limitations and Future Research

Our sample size was small at seven participants. It was impossible to parse out significant demographic information and for any of our findings to reach statistical significance. A larger sample size would allow expansion of analysis and data saturation. Uncommon responses could either be expanded to reach statistical significance or drop out as an insignificant finding.

The interviewee sample was biased in that it represented a very specific demographic: married, educated men who sought therapy. This homogenous population may have skewed the data. Recruiting from a more diverse population of men, especially those who have not already sought therapy would be useful for substantiating these preliminary findings. Also, we could encounter an altogether
different set of thoughts, ideas, and coping strategies in an expanded population of participants.

With one 50-minute interview, we only scratched the surface of each discussion area. Adding a second interview would have facilitated a greater understanding of each participants’ ideas, thoughts, and feelings. Two of the fathers mentioned during the interview that they had not thought about the experience or prepared for the interview ahead of time. They seem to have buried their emotions about the experience and having another interview would have certainly uncovered more intimate details about their responses to the experience. One father said that he would be happy to speak to another man in a similar experience but that he did not think that he would seek out that support. This contradiction in ideas shows that there were more layers to peel back in regards to how he felt about asking for support. This is just one example of a surface statement that could be more deeply explored in subsequent interviews.

Also, five of the interviews were conducted over the telephone. We did not notice a difference in the amount of information shared between the participants that were interviewed face-to-face, but it is not possible to quantitatively verify differences between these venues. Without eye contact and other non-verbal communication, it could have been difficult to build rapport and gain the participants’ trust throughout the conversation. In contrast, the extra confidentiality afforded by the telephone may have allowed the participants to express feelings they otherwise may not have explored.

Finally, it would have been useful to interview both members of the couple in order to compare and contrast the experiences between men and women. In the same
way that only exploring the mother’s feelings neglects the father’s perspective, only exploring the father’s point of view leaves out a major piece of the puzzle. It would have been interesting to have each partner’s perspective on his or her spouse’s grief process. Both members of the couple undergo the loss and subsequent grieving process, so having the story from each point of view would make the most complete picture of this experience.
CONCLUSION

This study explored the thoughts and feelings that the male partner has after experiencing termination of pregnancy for fetal anomaly. Although fathers may not tend to share their thoughts and feelings as openly as their partners, they do grieve the loss of the pregnancy in many of the same ways. Therefore, it is essential that genetic counselors make sure to counsel the couple as a unit and to take time to check in with the father. It may be helpful to point out the different coping mechanisms and strategies that fathers use to deal with grief. As noted in past studies, men often feel obligated to be strong and supportive, but when they take on this role they are criticized as being uncaring (Statham et al, 2000; McCoyd, 2007). Just because someone does not openly show emotion or take more time off of work does not mean they are not just as devastated about the loss as their partner. Genetic counselors can bring attention to this in order to dispel some of this pressure and stigma. We can help provide additional support by having a list of resources available including therapists, support groups, and other men who have gone through a similar experience. We can also keep these coping mechanisms in mind when starting support groups designed specifically for men. This study suggests that the male partners feel their role is to move the family forward and to keep normalcy in their daily lives. However, these interviewees also struggled with retelling their story and seeing other pregnant women or babies. Perhaps our culture and society inhibits men from exploring their feelings about their tragic losses,
but from our brief encounter these fathers had powerful and moving stories to tell. Each father experienced a long journey of grief alongside his partner.
REFERENCES


APPENDIX A
RECRUITMENT STATEMENT

I have been approached by a genetic counseling Masters student from Brandeis University who is conducting a study regarding the grief process that fathers experience after deciding to interrupt a pregnancy due to the presence of a fetal abnormality. After a brief contact by phone to schedule a meeting time, she plans to conduct one 50-minute interview with male partners interested in discussing their personal experiences.

I want to stress that participation is completely voluntary. I will never know if you decided to participate or not unless you choose to disclose that information to me. There is minimal risk involved in the study and no direct benefit to you. You will receive a $25 Visa gift card as a token of appreciation for donating your time. Are you interested in speaking with this student to find out more about the study?

If yes:

May I give the student your phone number so that she can contact you with more information about the study?

In no:

Thank you for your time and for considering this request.
APPENDIX B
PHONE INTAKE

Hello,

My name is Jennifer Desrochers. I'm a genetic counseling graduate student at Brandeis University. I'm conducting a research study about the grief process that fathers experience after deciding to interrupt a pregnancy as a result of a prenatal diagnosis of an abnormality. I know that Emily Lazar (or Terri Queler) has already briefly explained the study. Before, I tell you more about the study, do you have any initial questions for me?

The study involves participating in one 50-minute interview. The interview will be held at Emily's (or Terri's) office and will be audiotaped. Emily (or Terri) has agreed to meet with you free of charge to provide any additional support you may need as a result of this interview. I will not share with Emily (or Terri) whether or not you decide to participate; she won't know unless you choose to disclose the information or if you seek additional support from her. You will receive a $25 Visa gift card as a thank you for your time. The study is completely voluntary and confidential.

Did you have any questions about the study? Are you interested in participating? If yes, proceed to below. If no, ask about their reservations and thank them for their time.

Thank you for your willingness to speak about your experiences. In order to keep the interview within the time limit, I have a couple of questions to ask you. Is now a good time? If no, when should I call back?

Name:
Phone Number:
Email:

Age:
Occupation:
Relationship Status:
Number of Children:
Home State:

When would be a convenient time to schedule the interview?

Date/Time for Interview:
Address:
I would like to send you the informed consent form to review before your interview. What is the most convenient method for me to send you the form (mail, email, fax)? You may call or email me with any questions or concerns you have after reading the form.
APPENDIX C
INFORMED CONSENT FORM

BRANDEIS UNIVERSITY
DEPARTMENT OF BIOLOGY
GENETIC COUNSELING GRADUATE PROGRAM

Informed Consent to Participate in Research

PSYCHOSOCIAL IMPACT OF TERMINATION FOR FETAL ANOMALY ON THE MALE PARTNER

Principal Investigator: Janet Rosenfield, MS CGC
Student Researcher: Jennifer Desrochers

INTRODUCTION
Janet Rosenfield is a certified genetic counselor with experience specializing in prenatal diagnosis. She is also a faculty member for the Genetic Counseling Masters program at Brandeis University. Jennifer Desrochers is a Masters candidate in the Genetic Counseling program at Brandeis University. This is a research study exploring the feelings of grief and loss that men experience after they and their partner have elected to interrupt a pregnancy as a result of a prenatal diagnosis of an abnormality.

You are being invited to participate in this study because you are a male with a personal experience of ending a pregnancy based on a diagnosis of an abnormality. Taking part in this research study is totally your choice. You should not feel any pressure to participate. Your healthcare will never be impacted based on your decision to participate or not. You can decide to stop taking part in this research study at any time for any reason.

Please read all of the following information carefully. Ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form. You should keep your copy for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.
PURPOSE OF STUDY
The purpose of this study is to gain a better understanding of the thoughts and feelings that the male partner experiences following an interruption of pregnancy as a result of a prenatal diagnosis of abnormality. Our hope is that a better understanding of the grief process will lead to better health care and more appropriate referral of resources for couples in the future.

PROCEDURES TO BE FOLLOWED
You will be asked to participate in a face-to-face interview that will last approximately 50 minutes. The interview will take place at either Emily Lazar or Terri Queler's office. They will not be present at the time of the interview. You will be asked questions regarding your thoughts and feelings surrounding your personal experience. The interview will be audiotaped, transcribed, and studied.

RISKS
Participation in this study presents no more than minimal risk. However, it is possible that by taking part in this interview, you may experience distressing thoughts and feelings. Should this occur, Emily Lazar and Terri Queler are available to provide additional support. You may contact Emily Lazar at (617) 669-6573 or Terri Queler at (617) 699-8434.

BENEFITS
There will be no direct benefit to you for your participation in this study. We hope that in the future, information obtained from this study will help us gain a better understanding of male partners’ experiences of interrupting a pregnancy for fetal anomaly.

ALTERNATIVES
If you feel uncomfortable having a face-to-face interview, the student researcher will set up an interview over the phone. If you feel uncomfortable meeting at Emily Lazar or Terri Queler's office, the student researcher will set up an interview at Brandeis University. Another alternative is to not participate in this research study.

PRIVACY AND CONFIDENTIALITY
All identifying information will be kept strictly confidential and will be destroyed upon completion of this study. All identifying personal or demographic information will be changed in any written or oral reports based on the results of this study.

PAYMENT
You will receive a $25 Visa gift card for participation in the research study as a gesture of appreciation for your time and expertise.

COST
There will be no cost to you to participate in the study, other than the time it takes to be interviewed.
WHOM TO CONTACT
If you encounter any problems related to study participation or have questions about the study, you may contact the Student Researcher, Jennifer Desrochers at jendes@brandeis.edu.

You may also contact the Brandeis University Principal Investigator for this project, Janet Rosenfield, at jmrosenfield@mac.com.

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 781-736-8136.

PARTICIPANT’S STATEMENT
I have read this consent form and have discussed the procedures with Jennifer Desrochers described above. I have been given the opportunity to ask questions, which have been answered to my satisfaction. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement.

I understand that my participation is voluntary. I understand that I may refuse to participate in this study. I also understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so.

If I have any questions concerning my rights as a research subject in this study, I may contact the Brandeis Committee for Protection of Human Subjects by email at irb@brandeis.edu, or by phone at 781-736-8136.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above.

I understand that as a participant in this study my identity and data relating to this research study will be kept confidential.

Please initial here to indicate your willingness to be audiotaped.   


Date         Participant’s Signature


Date         Student Researcher’s Signature
APPENDIX D
INTERVIEW GUIDE

1. Can you tell me about the story of your loss from the beginning? Start with what brought you to genetics initially.

2. What were your initial thoughts after receiving the diagnosis?

3. Can you describe the decision making process with your partner? How far along was the pregnancy at the time of your loss?

4. In what ways did you get support?

5. Were there certain people that were more/less supportive during this time? (i.e. a friend, family members, significant other, clergy, counselor, grief group, no one)?
   a. How did you feel about that support or lack of support?

6. Can you describe what this loss has been like for you?
   a. How have you been managing to cope so far?

7. What did you find most difficult or hard to deal with?

8. How do you think your grief has evolved and changed over time?
   a. What ultimately helped you the most?
   b. Is there anything about this time you wished could have been different?

9. Do you think your grief process differed from your partner’s? Please describe.

10. How has this experience impacted your relationship with your partner?
    a. Did this experience have a positive or negative effect on the relationship?
    b. Do you think this experience has brought you closer or farther apart?
    c. Were there any specific roles you felt you needed to fulfill within your relationship during this time?

11. Has this loss impacted your decisions about future pregnancies? Please describe.

12. What would you like genetic counselors to understand about your experience, in order for us to provide better support to Fathers undergoing a pregnancy loss?