A Father's Response to Life-Limiting Fetal Diagnosis

Gracie Zvara

A Project presented to the faculty of

The University of North Carolina at Chapel Hill

in fulfillment of the requirements for

Undergraduate Honors

Date Completed: April 10, 2015

Honors Advisor Approval: Dr. Beth Perry Black

Abstract

The purpose of this project was to review the literature concerning paternal grief responses to life-limiting fetal diagnosis and subsequent perinatal loss. Content from two interviews with a bereaved father were used to illustrate major points from the literature. Specifically, this father experienced the diagnosis of fetal anencephaly at 17 weeks gestation; he and his partner chose to terminate the pregnancy. Both the literature and interviews suggest that the male partner can experience profound loss and grief. In particular, grief can be complicated because the man is grieving a child that he only knew through his partner's pregnancy, and the child isn't known to the world. Additional research is needed, but the grief of male partners should be recognized and support offered when a couple's expected child has a life-limiting diagnosis.

Introduction

The diagnosis of a life-limiting fetal condition is devastating (Sandelowski & Barroso, 2005). In this situation, the parents of the child typically have the choice of terminating the pregnancy or continuing the pregnancy until its natural end when she gives birth. In the case of a clearly lethal fetal defect, however, both paths lead to the same result: fetal or neonatal death. Although much research has been done on the responses of the woman to this type of loss as well as what needs she may have after the death of the expected infant, the responses and needs of the male partner have not been fully addressed.

Background

Incidence of Loss

There are many definitions of perinatal loss. Fetal mortality refers to the death of a fetus after 20 weeks gestation and prior to birth. Perinatal mortality refers to the death of a fetus or newborn baby from the point of viability (~23-24 weeks of gestation) to 28 days after birth, which is the end of the neonatal period. Fetal mortality rates have declined greatly in recent years; since 1990 stillbirths have decreased by 20% (Child Health USA, 2013). A miscarriage is defined as a pregnancy that ends in the first 20 weeks of gestation, and is the most common type of pregnancy loss (American Pregnancy Association). A stillbirth is when fetal death takes place after the 20th week of gestation (March of Dimes).

It is difficult to ascertain statistics on miscarriage in the United States as many miscarriages occur without the mother even knowing she was pregnant.

However, the Center for Disease Control does keep statistics on stillbirths. In 2006, there were 25,972 reported fetal deaths at 20+ weeks of gestation (CDC, 2006). Since 2006, there has not been any significant additional decline in fetal death rates (CDC, 2014). Despite the statistics on fetal death rates, it is difficult to ascertain how many women choose to continue their pregnancies in the wake of a diagnosis of a life-limiting fetal defect, as opposed to termination of the pregnancy.

Definition of Loss

Defining "death" can be difficult. Death means many things all over the world and has cultural implications. For example, in Hinduism, life and death are a circular process and upon death, one is reincarnated with a new identity (Gire, 2002). Alternatively, some cultures believe that various forms of death happen throughout life before the final death, and classify events such as illness and deep sleep as forms of death (Gire, 2002).

However, the World Health Organization defined death in the 1950s as the end of life after birth has taken place (Leming & Dickinson, 2007). Although this definition of death seems to be comprehensive, it excludes the end of fetal life. A separate fetal death definition became necessary, now typically defined as "disappearance of life prior to the expulsion…from its mother" (Stockwell, 1976).

There are a variety of fetal diagnoses that threaten to limit the life of the fetus or neonate if live-born. Severe diagnoses include central nervous system defects such as anencephaly (absence of the brain) and acrania (absence of the skull),

bilateral renal agenesis (failure of the kidneys to develop), certain severe heart defects, gastrointestinal defects, and diaphragmatic hernia, among many others.

The Case of One Father

For this paper, I focused on one father who experienced the wide range of emotions that come with life-limiting fetal diagnosis. He and his wife were expecting their second child when they received the diagnosis of anencephaly during the ultrasound scan for fetal anatomy at 17 weeks of gestation. Anencephaly is a form of neural tube defect where the fetus develops without substantial brain or skull matter (CDC, 2014). It is a very severe condition and most babies will die shortly after birth (CDC, 2014). It has been linked to folic acid deficiency during pregnancy, and as more foods have become fortified with folic acid, the incidence of anencephaly has decreased (CDC, 2000).

Upon receiving this diagnosis, the father and his wife were devastated. After counseling with their pastor and discussing the diagnosis with their close family, they decided to terminate the pregnancy by inducing labor. His wife delivered the fetus prematurely at around 18 weeks gestation and the baby died immediately. This father was interviewed 2 weeks after the loss and again 6 months later. Immediately after the birth, the father was in shock but his primary concern was taking care of his equally devastated wife; however, 6 months later the loss was becoming more real to him. In this paper, I compare his grief response to the men's responses described in the literature on perinatal loss. The two interviews were a small part of a larger study conducted in 2006; the IRB was consulted and deemed

use of this de-identified data in this manner not human subjects research. Quotes from the interviews are indicated by "*In the father's words:".*

Distress and Grief after Life-limiting Fetal Diagnosis

Expectant mothers and fathers may experience great distress after the diagnosis of a life-limiting fetal condition (Pelly, 2003). Depending on the outcome of the pregnancy and the survival of the fetus, this distress can range from anxiety to the profound sadness of grief. Grief includes a variety of responses to death; the "emotional, cognitive, and somatic aspects of a person's response to death" (Jacobs, Mazure & Prigerson, 2000). More simply, grief is the sadness associated with a loss. Bereavement is the state of being after a loss, generally by death, in which grief is expressed. Mourning is the outward evidence of grieving and is culturally determined; for example in the United States wearing black is a symbol of mourning. Separation distress includes crying, loneliness, and pangs of yearning, is precipitated by a loss and is essential to grief (Jacobs, Mazure & Prigerson, 2000).

Life-threatening or severe prenatal diagnosis may be conceptualized as multiple losses rather than one loss (Cote-Arsenault & Denney-Koelsche, 2011). They claimed that expectant parents grieve the losses of their imagined healthy baby, a normal pregnancy experience, and the imagined future parenting process (Cote-Arsenault & Denney-Koelshe, 2011). Mothers also mourn the loss of the "ideal" baby without abnormal diagnosis (Keefe-Cooperman, 2004).

> *In the father's words:* She was a lost granddaughter. A lost niece. A lost part of the family...This is the loss of a child….to watch her little heart stop was heartbreaking, heartbreaking. All the vacation wasn't going to be the same, Christmas wasn't going to be the same.

Grief is experienced with the stillbirth of the fetus as well. Brier (1998) claimed that although descriptions of grief following fetal loss are variable, they "match" descriptions of other types of grief. A qualitative evaluation of 44 women treated for miscarriage around 2 weeks after the event felt a sense of loss 82% of the time which had an impact on daily functioning as a result of that loss (Zaccardi, Abbott & Kozial-McLain, 1993). Kersting and Wagner (2012) supported Brier's assertion that grief after fetal loss is not different from other forms of loss. In fact, perinatal loss is associated with depression, post-traumatic stress disorder, and anxiety among parents (Kersting & Wagner, 2012).

> *In the father's words:* …the loss was so devastating, we were just going to hang onto everything we could. Just wanted to grab plastic wrap around the house and be by ourselves and not let anybody touch us…I think we didn't want to interact, out of fear, we didn't want to waste a minute of us being a family together. We didn't want to risk any pain, any harm, any of that.

Parents also reported feeling socially isolated after perinatal loss and felt a lack of social support (Cacciatore, 2013). This isolation and experience of somatic

symptoms in general can last far longer than the immediate post-partum period; some parents feel symptoms for decades after the loss (Cacciatore, 2013). In one study, one third of mothers evaluated had a severe deterioration in their physical and mental well-being after experiencing perinatal loss. However, this father experienced overwhelming social support from family and friends and discovered that more people than he had realized had experienced similar pregnancy loss.

> *In the father's words:* I bet we had to receive over 200 cards. And we are still eating food out of our freezer because people just brought us so much and we had a memorial service for her that we thought it would be a couple of neighbors, close friends, and our family. The church was filled….I've been just blown away by the people who have called and come up and said we know, not necessarily exactly what we're facing, because not all of them do, but so many people coming up and saying they've lost a child at some point during the pregnancy.

Perinatal loss has effects on family systems as well. In fact, it can result in divorce (Nicol, Tompkins, Campbell & Syme, 1986). Between 40-50% of couples in the United States will get a divorce (American Psychological Association). Many couples have strain and stress within their relationship that predate a perinatal loss. The combining of those problems with the unique stress of perinatal loss could be devastating for some. Gold, Sen, and Hayward (2010) supported this notion, indicating that women who have a stillbirth or miscarriage have a significantly

greater chance of their relationship ending. Women who have miscarriages can be affected between 1.5-3 years after the loss, but those who have stillbirths can feel the effect on their marriage up to 9 years after the loss (Gold, Sen & Hayward, 2010).

Gold, Sen, and Hayward (2010) hypothesized that the difference in length of time affected by the loss is that with a stillbirth, the parents have more opportunity to form a relationship with the fetus as the pregnancy progresses and it kicks and is felt as a separate being. With a miscarriage, the fetus is not felt in the same way and the pregnancy itself may still feel unreal. However, in this instance, the male partner felt as though the loss brought him and his wife even closer together.

> *In the father's words:* …what has happened with the loss of [our baby] is kind of reassuring us that our family is not defined by the children, the family is defined by all of us and we've talked often about having a marriage centered family and not a child centered family.

Not only are relationships and marriages affected greatly by perinatal loss, but existing and future children are affected deeply as well. O'Leary and Gaziano (2011) assert that existing children actually experience two losses, the loss of the expected sibling and the loss of their parents as they knew them before the loss. This profound loss felt by the existing children is usually complicated in the sense that their bereaved parents are too grief-stricken to explain what happened to the child and the child can be left feeling helpless (O'Leary & Gaziano, 2011). The

subject's existing child was a toddler at the time and therefore was not interviewed on her feelings regarding the loss.

In research on parental response to subsequent pregnancy after perinatal loss, fathers experienced elevated levels of post-traumatic stress disorder and anxiety when compared to those who have not experienced perinatal loss, however those symptoms resolved after the birth of a health baby (Turton et al., 2006). On the other hand, mothers who had experienced perinatal loss continued to experience symptoms of anxiety, PTSD, and depression even after the birth of a subsequent healthy child (Hughes, Turton & Evans, 1999). Women can also be skeptical of their ability to have a healthy baby, and have difficulty believing the current pregnancy will be successful (Cote-Arsenault, Bidlack & Humm, 2001). Early pregnancy (within one year) after a perinatal loss is associated with an increase in levels of depression in the women studied (Cote-Arsenault, Bidlack & Humm, 2001). Levels of depression decrease if at least a year has passed (Hughes, Turton & Evans, 1999). In the case of this bereaved expectant father, his wife conceived only six months after the loss, and subsequently had a miscarriage.

> *In the father's words (first interview):* We definitely want more children...[my wife] said next time I'm going to be a nervous wreck. I'm going to be worried about every little thing…I think she said maybe by the end of the year, we'll start trying.

> *In the father's words (second interview:* Hindsight being what it is…maybe six months was a little too soon to try again. It could've been three months, could've been a year, we could have still lost the pregnancy, you don't know.

Differences in Grief Between Fathers and Mothers

While life-limiting fetal diagnosis is traumatic for parents, grief is experienced differently between mothers and fathers (Leming & Dickinson, 2007). Leming and Dickinson (2007) defined mourning as "moderated by identification," meaning that the deceased is mourned by the living remembering aspects of their personality and livelihood that will be missed. Because a fetus or neonate has not had time to develop as a separate individual, however, the parents have no unique identity to mourn, and thus their grief is seemingly invalidated. In fact, Leming and Dickinson (2007) asserted that this is a large part of why grieving parents do not receive as much validation for their fetal or neonatal loss. This concept is referred to as "ambiguous loss," defined as an "incomplete or uncertain loss" (Boss, 1999). The loss is confusing not only to the parents involved but to the outside world as well.

A similar concept is disenfranchised grief, which is grief that is experienced when one has a loss they feel cannot be acknowledged, mourned openly, or for which they don't receive social support (Doka, 1989). Sandelowski and Black (1994) also discussed the parents' unique relationship with their fetus, which supports the concepts of ambiguous and disenfranchised grief. Although the mother and father know the fetus through its development, that knowledge is not apparent

to the outside world, thus seemingly invalidating their grief upon fetal loss (Sandelowski & Black, 1994). More specifically, while the female partner experiences the pregnancy in its entirety and "knows" the fetus throughout the duration, the male partner only begins to experience "knowing" the baby physically midway through the pregnancy when the fetus exhibits outer physical signs like kicking and other movements. However, this father described feeling like his child was real from the outset of the pregnancy.

> *In the father's words:* It's a different loss…because of the relationship that I had with [the fetus] even though she was just in my wife's tummy. We were reading stories to her and we were talking about it, and we were planning our summer vacation. And she was very real to us…from the day we found out we were pregnant. It…from day one, this was a pregnancy. It was a child. And we would watch…week number two was happening now in the development and she's the size of a peanut and she's the size of an apple seed and all these things…but in my mind, she was a little baby. She didn't look like an apple seed or she didn't look like a peanut…from day one, I was your daddy.

Some researchers have examined the thought processes behind men and women choosing to disclose or not disclose the circumstances of their pregnancy loss. France, Hunt, Ziebland, and Wyke (2011) interviewed women and men who had terminated a pregnancy due to a severe fetal abnormality and found a variety of

responses regarding disclosure of this information. Most disclosed only to close friends and family who knew of the pregnancy as well as those they knew had experience with fetal loss. However, some chose not to disclose either due to guilt over the decision and fear of being judged, or the desire to protect other people's feelings (France, Hunt, Ziebland & Wyke, 2011). Those who did tell others expressed that they received "more support and less criticism than expected" (France, Hunt, Ziebland & Wyke, 2011). The men in the study in particular did note that they found it more difficult to disclose than their female partners because of the weight of social expectations of how men ought to deal with their feelings (France, Hunt, Ziebland and Wyke, 2011).

> *In the father's words:* I called my parents right away…they were just in disbelief…it gave us a chance to begin grieving right then and there. But as tired as I got of telling the story, I didn't want to talk to anybody without telling the story. Because it made [the baby] real….at least there's a story about her. There's still something very real and tangible. And there were people crying over her. And people were asking about her…And that's all I remember of that weekend, is being on the phone but being selective about who we would talk to. We did not tell friends about it at that point. Because you don't always know people's political views…but I told [the story] 20 times in those couple of days. It was absolutely exhausting and draining. But, it got me to…begin the grief process.

The confusion of choosing to disclose or withhold information from friends and family is further complicated by interactions with health care providers. Many parents who chose to continue their pregnancies after learning of life-limiting fetal conditions reported disappointment in how health care providers responded to their choices after diagnosis. For example, in a study by Guon, Wilfond, Farlow, Braze and Janvier (2013), 37% of parents who opted for clinical intervention despite their fetus' life-limiting diagnosis felt judged by their health care provider.

Many parents reported the health care providers didn't see their children as "unique;" rather the health care providers would refer to their child as their diagnosis (Guon et al., 2013). In this study, 23% of parents reported that health care providers advised them that continuing the pregnancy in light of life-limiting diagnosis would "ruin their family" (Guon et al., 2013). The parents in this study continued their pregnancies for a variety of reasons, the top four being reasons related to moral beliefs, child-centered beliefs, parent-centered beliefs, or practical reasons (inability to terminate the pregnancy). In fact, an estimated 20-85% of mothers carrying a fetus with a life-limiting fetal diagnosis lack the legal ability to terminate the pregnancy due to the state's limits on gestational age (Cote-Arsenault & Denny-Koelsch, 2011).

Supportive health care providers can make a huge difference, however. According to Murray and Callan (1988), parents who felt they were supported adequately by medical staff after a termination or stillbirth were less depressed, had fewer grief reactions, and overall better psychological well-being than those who reported not being supported.

> *In the father's words:* They [hospital employees] said you can keep her with you as long as you want. And I'm really grateful for that. [The whole family] got a chance to hold her and we had a little prayer service…while she was there. And again, that made her part of the family…[the hospital] took photos for us, and they did a hand imprint and her foot imprint that we kept as well…I saw more attention in care and sympathy and tenderness and love from the hospital staff than we had experienced with our first [child]….the doctors were incredible. The nurses, the students who came in were just so sympathetic to our situation…so that whole piece made us feel like we weren't alone where I think we could have easily felt alone in that process.

Paternal Response to Perinatal Loss

Although much of the research on perinatal loss focuses on the emotional well-being of the female partner or the parental unit, some work has been done to examine the role of the male partner in the wake of life-limiting diagnosis. The level of grief experienced by male partners is moderated by the length of the pregnancy prior to the loss as well as the use of ultrasounds to visualize the fetus (Johnson & Puddifoot, 1996). There are also many differences in how men and women manifest grief. For example, men have been found to cry less, experience less distress when seeing other pregnant women, and have less of a need to talk about the fetal loss (Beutel, Willner, Deckardt, VonRad & Weiner, 1996).

Kersting and Wagner (2012) found that men are likely to turn their grief inward or deny it completely, through distraction or avoiding the topic altogether. Nazaré, Fonesca, and Canavarro (2013) identify two such reasons for men to turn their grief inward: societal norms (Gilbert, 1989; White-Van Mourik et al., 1992) and their supporting role [in the pregnancy] (Abboud & Liamputtong, 2003; Desrochers, 2011; Korenromp et al., 1992; McCreight, 2004; Murphy, 1998). Male partners are also found to take insufficient time off from work and possibly use work as a coping mechanism (Colon, 2008). Turton et al. (2006) found that many male partners increased their alcohol consumption and prescription drug use to cope with the loss. Additionally, 47.4% of male partners received therapy of some kind (Turton et al., 2006).

> *In the father's words (first interview):* I'm trying to tend to [my wife] because I think the issue with her having carried [our baby] around is a little bit more immediate and she needs that focus right now…I can beat the hell out of a racquetball and kind of get some of it out. Not that I'm suppressing my feelings, but I'm really trying to focus on her and help her through the most critical stage…I can begin healing later. I can manage it.

A connection likely exists between emotional pain and physical pain as well. Although physical pain can lead to negative emotions such as anxiety and depression, Wiech and Tracey (2009) noted that the reverse may be true as well- that negative emotions can both cause pain and exacerbate it. Approximately 4

months after the pregnancy loss, this father developed a cold that lasted for several weeks and then developed serious neuropathic back pain. When asked if he believed the stress of the year had anything to do with his intense physical pain, he responded "…it's definitely related, there's no doubt in my mind."

As noted by Brier (2008), there are contradictions found in the literature regarding the male experience of grief after fetal loss. Although some studies indicate men experience more intense grief than women do, most show that men experience less intense grief as well as for a shorter period of time than their female counterparts. Fathers are also noted to be particularly susceptible to disenfranchised grief, because they did not carry the fetus themselves and the loss is physically seen in their partners, not in them (Colon, 2008). Fathers are often responsible for the practical matters of the fetal loss, such as arranging the funeral and brokering information to others, and thus are too busy to acknowledge their own grief (Colon, 2008).

> *In the father's words:* I stood in a vacant birthing suite, that…night. [My wife] had been induced and we were waiting for her to give birth. And I stood in that room and called a funeral home back home…And running through my head is, you're [xx] years old and you're on the phone with the funeral parlor to make arrangements for your dying child. No…person should have to experience that. No…person should have a funeral home stored in their cell phone. I was standing in the birthing suite talking to a funeral home…that constant conflict of circumstances was just absolutely amazing.

Discussion and Clinical Implications

This literature review shows differences in the ways that expectant mothers and fathers experience perinatal loss. The father quoted in this paper demonstrated much of this phenomenon. He experienced two losses: the first fetus to anencephaly and the second in an early miscarriage. His risk for complicated grief increased significantly with the second loss. However, it seemed as though the first pregnancy loss was far more traumatic for him than the miscarriage, possibly due to the gestational age of the first pregnancy. The father confided that he would like to try for another pregnancy, although he reported that his wife would rather adopt.

Although this man's experience was very similar in some ways to what has been described in the literature, he had significant departures as well. Most similar to the literature was this father's desire to protect his wife first and look after her emotional response before addressing his own feelings of loss and grief. Although some men have been described in the literature as experiencing the hospital staff being unsupportive in the instance of life-limiting prenatal diagnosis, this man had the opposite experience. This may suggest that he might have a less difficult time coping with the loss over time.

Two pivotal interventions by the hospital staff were allowing him and his family time with the baby after the delivery as well as allowing them to hold a small bedside memorial service. The man also described how supported he felt by family and friends from receiving cards and freezer meals to a funeral service that packed

the church. The recognition of his loss allowed him to share his pain, unlike other fathers in the literature who felt they needed to keep their grief to themselves.

Although women are the physical carriers of the pregnancy and surely experience much grief in the instance of life-limiting prenatal diagnosis, it is clear that men experience grief as well which needs to be recognized by healthcare providers. Ways to recognize this loss include expressing sorrow not just to the couple but to the woman and her partner individually. Also, allowing the parents to take time with their baby after the delivery is important. Fathers should also be offered the same resources as the mothers under these circumstances, such as information on grief and bereavement centers, support groups and hotlines.

It is clear that there are important opportunities to learn more about the paternal grief response to life-limiting prenatal diagnosis as well as appropriate clinical interventions. Not enough has been done yet to learn about the grieving male partner and the effects that clearly last far longer than the immediate post-partum period.

References

Abboud, L. N., & Liamputtong, P. (2003). Pregnancy loss: What it means to women who miscarry and their partners. *Social Work in Health Care*, *36*, 37–62. doi:10.1300/J010v 36n03_03

American Pregnancy Association. (2014). *Miscarriage*. Retrieved from http://americanpregnancy.org/pregnancy-complications/miscarriage/

American Psychological Association. (n.d.). *Marriage and Divorce.* Retrieved from http://www.apa.org/topics/divorce/

Beutel, M., Willner, H., Deckardt, R., VonRad, M., & Weiner, H. (1996). Similarities and differences in couples' grief reactions following a miscarriage: Results from a longitudinal study. *Journal of Psychosomatic Research, 40*(245). doi: 10.1016/0022-3999(95)00520-X

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Retrieved from http://site.ebrary.com/lib/uncch/reader.action?docID=10314197

Brier, N. (2008). Grief following miscarriage: A comprehensive review of the literature. *Journal of Women's Health*, *17*(3), 451-464. doi: 10.1089/jwh.2007.0505

Cacciatore, J. (2013). Psychological effects of stillbirth. *Seminars in Fetal and Neonatal Medicine*, *18*(2), 76-82. doi: 10.1016/j.siny.2012.09.001

Child Health USA. (2013). *Fetal mortality.* Retrieved from http://mchb.hrsa.gov/chusa13/perinatal-health-status-indicators/p/fetal-mortality.html

Centers for Disease Control and Prevention. (2014). *Facts about anencephaly.* Retrieved from http://www.cdc.gov/ncbddd/birthdefects/anencephaly.html

Centers for Disease Control and Prevention. (2012). *Fetal and perinatal mortality, United States, 2006.* Retrieved from http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_08.pdf

Centers for Disease Control and Prevention. (2004). *Spina bifida and anencephaly before and after folic acid mandate - United States, 1995--1996 and 1999—2000*. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5317a3.htm

Centers for Disease Control and Prevention. (2014). *Trends in fetal and perinatal mortality in the United States, 2006-2012.* Retrieved from http://www.cdc.gov/nchs/data/databriefs/db169.pdf

Colon, E. J. (2008). *Paternal experiences after a perinatal loss* (Doctoral dissertation). Retrieved from ProQuest Digital Dissertations. (UMI 3321393)

Cote-Arsenault, D., Bidlack, D., & Humm, A. (2001). Women's emotions and concerns during pregnancy following perinatal loss. *American Journal of Maternal Child Nursing*, *26*(3), 128-134. Retrieved from http://journals.lww.com/mcnjournal/Abstract/2001/05000/Women_s_Emotions_and_Concerns_During_Pregnancy.6.aspx

Cote-Arsenault, D., & Denney-Koelsch, E. (2011). "My baby is a person": Parents' experiences with life-threatening fetal diagnosis. *Journal of Palliative Medicine*, *14*(12), 1302-1308. doi: 10.1089/jpm.2011.0165

Desrochers, J. N. (2011). *The psychosocial impact of termination of pregnancy for fetal anomaly on the male partner* (Master's thesis). Retrieved from https://bir.brandeis.edu/bitstream/handle/10192/24389/DesrochersPsychosocialImpactOfTOP.pdf?sequence=1

France, E.F., Hunt, K., Ziebland, S., & Wyke, S. (2011). What parents say about disclosing the end of their pregnancy due to fetal abnormality. *Midwifery, 29*(1), 24-32. doi: 10.1016/j.midw.2011.10.006

Gilbert, K. (1989). Interactive grief and coping in the marital dyad. *Death Studies*, *13*, 605– 626. doi:10.1080/07481188908252336

Gire, J.T. (2002). How death imitates life: Cultural influences on conceptions of death and dying. In *Online Readings in Psychology and Culture* (Unit 14, Chapter 2). Retrieved from http://www.wwu.edu/culture/gire.htm

Gold, K. J., Sen, A., & Hayward, R. A. (2010). Marriage and cohabitation outcomes after pregnancy loss. *Pediatrics, 125*(5), 1202-1207. doi: 10.1542/peds/2009-3081

Guon, J., Wilfond, B. S., Farlow, B., Brazg, T., & Janvier, A. (2013). Our children are not a diagnosis: The experience of parents who continue their pregnancy after a prenatal diagnosis of Trisomy 13 or 18. *American Journal of Medical Genetics*, *164*(2), 308-318. doi: 10.1002/ajmg.a.36298

Hughes, P. M. & Turton, C. D. H. (1999). Stillbirth as a risk factor for depression and anxiety in the subsequent pregnancy: Cohort study. *The British Medical Journal, 318*: 1721. doi: 10.1136/bmj.318.7200.1721

Jacobs, S., Mazure, C., & Prigerson, H. (2000). Diagnostic criteria for traumatic grief. *Death Studies, 24*(3), 185-199. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11010626

Johnson, M. P. & Puddifoot, J. E. (1996). The grief response in the partners of women who miscarry. *British Journal of Medical Psychology*, *69*(4), 313-327. doi: 10.1111/j/2044-8341.1996.tb01875.x

Keefe-Cooperman, K. (2004). A comparison of grief as related to miscarriage and termination for fetal abnormality. *Omega Journal of Death and Dying, 50*(4), 281-300. doi: 10.2190/QFDW-LGEY-CYLM-N4LW

Kersting, A., & Wagner, B. (2012). Complicated grief after perinatal loss. *Dialogues in Clinical Neuroscience*, *14*(2), 187-194. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3384447/

Korenromp, M. J., Iedema-Kuiper, H. R., van Spijker, H. G., Christiaens, G. C. M. L., & Bergsma, J. (1992). Termination of pregnancy on genetic grounds: Coping with grieving. *Journal of Psychosomatic Obstetrics and Gynecology*, *13*, 93–105. Retrieved from http://informahealthcare.com/doi/abs/10.3109/01674829209016709

Leming, M.R. & Dickinson, G. E. (2007). *Understanding dying, death, & bereavement* (6th ed.). Belmont, CA: Thomas Wadsworth

March of Dimes. (n.d.). *Pregnancy loss.* Retrieved from http://www.marchofdimes.org/loss/stillbirth.aspx#

McCreight, B. S. (2004). A grief ignored: Narratives of pregnancy loss from a male perspective. *Sociology of Health & Illness*, *26*, 326–250. doi:10.1111/j.1467-9566.2004.00393.x

Murphy, F. A. (1998). The experience of early miscarriage from a male perspective. *Journal of Clinical Nursing*, *7*, 325–332. doi:10.1046/j.1365-2702.1998.00153.x

Murray, J., & Callan, V. J. (1988). Predicting adjustment to perinatal death. *British Journal of Medical Psychology*, *61*(3), 237-244. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/3179246

Nazaré, B., Fonseca, A., & Canavarro, M.C. (2013). Adaptive and maladaptive grief responses following TOPFA: actor and partner effects of coping strategies. *Journal of Reproductive and Infant Psychology, 31*(3), 257-273. doi: 10.1080/02646838.2013.806789

Nicol, M. T., Tompkins, J. R., Campbell, N. A., & Syme, G. J. (1986). Maternal grieving response after perinatal death. *The Medical Journal of Australia*, *144*(6), 287-289. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/3713619

O'Leary, J. M. & Gaziano, C. (2011). Sibling grief after perinatal loss*. Journal of Prenatal and Perinatal Psychology and Health*, *25*(3), 173-193. Retrieved from http://momenough.com/wp-content/uploads/2012/01/Sibling-Grief-after-perinatal-loss.pdf

Pelly, D. (2003). Women's experiences of fetal abnormality. *British Journal of Midwifery*, *11*(3), 154-159. doi: 10.12968/bjom.2003.11.3.11125

Sandelowski, M. & Barroso, J. (2005). The travesty of choosing after positive prenatal diagnosis. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 34*(3), 307-318. doi: 10.1177/0884217505276291

Sandelowski, M., & Black, B.P. (1994). The epistemology of expectant parenthood. *Western Journal of Nursing Research*, *16*(6), 601-622. doi: 10.1177/019394599401600602

Stockwell, E.G. (1976). *The methods and materials of demography.* New York: Academic Press

Turton, P., Badenhorst, W., Hughes, P., Ward, J., Riches, S., & White, S. (2006). Psychological impact of stillbirth on fathers in the subsequent pregnancy and puerperium. *British Journal of Psychiatry*, *188*: 165-172. doi: 10.1192/bjp.188.2.165

White-Van Mourik, M. C. A., Connor, J. M., & Ferguson-Smith, M. A. (1992). The psychosocial sequelae of a second-trimester termination of pregnancy for fetal abnormality. *Prenatal Diagnosis*, *12*(3), 189–204. doi:10.1002/pd.1970120308

Wiech, K., & Tracey, I. (2009). The influence of negative emotions on pain: Behavioral effects and neuromechanisms. *Neuroimage, 47*(3), 987-994. doi: 10.1016/j/neuroimage.2009.05.059

Zaccardi, R., Abbott, J., & Kozial-McLain, J. (1993). Loss and grief reactions after spontaneous miscarriage in the emergency department. *Annals of Emergency Medicine, 22*(5), 799-804. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/8470836