Published in final edited form as:

J Genet Couns. 2008 October ; 17(5): 419–423. doi:10.1007/s10897-008-9170-3.

Commentary on “My Story: A Genetic Counselor’s Journey from Provider to Patient”

Barbara Bowles Biesecker

National Human Genome Research Institute, Bethesda, MD, USA

The anonymous author of, “My story: A genetic counselor’s journey from provider to patient,” deserves our deepest respect and admiration (Anonymous 2008). The author has endured a tortuous decision and its consequences, and has found the courage to publish her journey. This commentary addresses themes that arise from her story, draws upon the research literature and highlights what genetic counselors and other health care providers can learn from her experiences.

Overall, the author helps genetic counselors understand more intimately what it might be like for patients making decisions whether or not to end a pregnancy. She facilitates an opportunity for empathic understanding of our patients’ experiences. Most importantly, the author demonstrates the need for a most essential counseling skill; our capacity for compassion towards others (Kessler 1999). As a genetic counselor, her journey is also a painful reminder that as providers we are not exempt from the suffering experienced by our patients. The author is able to help us recognize strategies that may better help our patients who are living with the consequences of difficult decisions.

The literature is replete with commentaries and studies published by professionals as patients recounting their experiences when the “shoe was on the other foot.” (Beatty 2004; Guttmacher 2000; Klitzman 2006; McKeivitt and Morgan 1997). From these reports we can gain insight into our professional work and its consequences because of the patient’s unique ability to describe her/his experience from two vantage points. Guttmacher, a medical geneticist, offers twenty lessons to fellow physicians following his experience as a cardiac patient (Guttmacher 2000). The descriptions of his medical events vividly place the reader in the situation with him, feeling his vulnerability. He is able to use his vantage point of being a physician to relate his experiences to his peers. One can only imagine practicing medicine with a heightened awareness of the patient’s experience upon reading his lessons.

Often such commentaries facilitate our empathic understanding of patient experiences from which we, as health care providers, tend to feel exempt. A qualitative study by McKeivitt and Morgan uncovered a general attitude among health care providers that illness does not belong to them (McKeivitt and Morgan 1997). Beatty reminds us otherwise as he describes the impact of his vision loss on his medical practice and on his personal identity (Beatty 2004). “...the utility of suffering is that it helps us sharpen our internal focus to more clearly see the true contours of our lives.... If illness changes our identities and the way we look at life, let us try to profit from the change emotionally and learn from the different perspective it gives us... There are always lessons to be learned” (Beatty 2004). Klitzman reports findings from a study of doctors who become patients, demonstrating how these experiences can lead to improvements in doctor-patient relationships (Klitzman 2006). Outcomes of his study included

the suggestion that physicians address more fully the cognitive and emotional aspects of their patients' health experiences.

The author's journey is conveyed with contextual precision (Anonymous 2008). We learn about each setting, the people and procedures associated with her pregnancy termination. We can envision the picketer, security guard, providers, rooms, and procedures. The surroundings, including people's words, are emblazoned in her memory. She allows us to envision each scene as it unfolds. Perhaps she intended to help genetic counselors use these images to reduce our patients' uncertainty in similar circumstances or to help them develop realistic expectations. More importantly, perhaps the author intended for genetic counselors to help their clients understand what they might face in terminating a pregnancy and the significant impact that it may have on their lives. Her story provides a profound perspective on several themes previously identified in research studies addressing the experience of termination following the diagnosis of a fetal abnormality.

A number of studies describe the decision to end a pregnancy when a fetus is diagnosed with a fetal anomaly and the consequences of that decision (Dallaire et al. 1995; Davies et al. 2005; Elder and Laurence 1991; Hunfield et al. 1994; Iles and Gath 1993; Kersting et al. 2005, 2007; Korenromp et al. 2005, 2007; McCoyd 2007; White-Van Mourik et al. 1992; Zeanah et al. 1993). Overall they suggest that what surrounds the abortion is bereavement parallel to other perinatal loss, with additional feelings of guilt, responsibility and anxiety that can lead to symptoms of post-traumatic stress. These reactions have been described as complex or protracted grief and have important implications for genetic counselors.

Diagnosis of a fetal abnormality is devastating. Parents are thrown into a crisis during which they most often face the hardest decision of their life. While women generally cope successfully with the stress of abortions for unwanted pregnancies (Adler and David 1992), abortions in the case of fetal anomalies present a different picture. In this case, pregnancies are generally desired, the women and their partners have bonded with the developing fetus and have begun to invest emotionally in their future expanded family. These couples differentiate themselves from those who abort unwanted pregnancies and associate themselves with those who have experienced perinatal loss of a desired pregnancy (Sandelowski and Barroso 2005). In a longitudinal study conducted in Norway, researchers found that the long term psychological distress in women who terminated their pregnancies following ultrasound identification of fetal abnormalities (N=24) differed in no way from that of women experiencing a perinatal loss (N=29; Salvesen et al. 1997). Similarly, Zeanah and colleagues found that women who had terminated for fetal abnormality (N=23) grieve as intensely as those who experience spontaneous perinatal loss (N=23 matched control; Zeanah et al. 1993).

Similar to perinatal loss of any desired pregnancy, initial reactions to the identification of an abnormality are disbelief and shock. These reactions extend into the period of the termination and following. McCoyd described a period of shock once women decided to terminate, that extended for up to three weeks after the termination (McCoyd 2007). Similarly, White-Van Mourik and colleagues found that women commonly described not being able to feel anything after the termination (White-Van Mourik et al. 1992). Others described feeling significant distress following the procedure (Iles and Gath 1993). These grief reactions are common following any perinatal loss, however research suggests that they may be more complex and protracted following termination for fetal abnormality.

Grief reactions following terminations are significant and well-documented. Kersting and colleagues assessed the reactions of 62 women who had undergone a termination for fetal abnormality compared with those of 65 women who had delivered a full-term healthy baby (Kersting et al. 2007). Grief, posttraumatic stress, depression, anxiety and psychiatric disorders

were evaluated at 14 days, 6 months and 14 months afterward. Women who terminated their pregnancy reported significantly more negative psychological well-being at each time point. Notably, 14 months after termination 14% of the women met criteria for a complicated grief reaction. This has been defined as the experience, more than a year after a loss, of intense intrusive thoughts, pangs of severe emotion, distressing yearnings, extreme loneliness, excessively avoiding tasks reminiscent of the deceased, unusual sleep disturbances, and significantly lost interest in personal activities (Horowitz et al. 1997). Seventeen percent of participants in Kersting's study met the criteria for a psychiatric disorder as defined by the DSM-IV (Kersting et al. 2007). A study by Dallaire and colleagues in Quebec found that 19% of participants (N= 76) expressed a need to see a psychiatrist following termination for fetal abnormality (Dallaire et al. 1995). Similarly, Elder and Laurence found that 25% of women (N=69) in the UK terminating pregnancies in the second trimester had unresolved grief reactions six months afterward (Elder and Laurence 1991). Perceived personal control over perinatal death in the case of fetal abnormality was not associated with outcomes three months after termination in a study of 30 women (Hunfield et al. 1994), suggesting little perceived benefit to having had a choice on the intensity of one's grief reactions.

One qualitative study of 86 parents from the Netherlands distinguishes itself from the others (Geerinek-Vercammen and Kanhai 2003). Most signs of negative psychological well-being were gone by 6 months following termination. Participants recounted seeing the baby to say good-bye and the care they received from their health care providers as valuable in facilitating their recovery.

Davies and colleagues compared psychological outcomes between women who underwent first trimester abortions after detection of anomalies detected on ultrasound (N=14) to those that had second trimester abortions (N=16; Davies et al. 2005). Women who underwent a second trimester abortion had significantly higher levels of post-traumatic stress symptoms six weeks after termination. Both groups demonstrated psychological morbidity that persisted through a 12-month assessment. Kersting and colleagues found higher levels of intrusion (40%) and avoidance (24%), with 47% of women displaying both (Kersting et al. 2005). Sadness and guilt had a significant influence on the degree of intrusion whereas guilt and anger influenced avoidance reactions.

One longitudinal study conducted in the Netherlands assessed outcomes for 196 women between 2–7 years post termination for fetal abnormality (Korenromp et al. 2005). Findings suggest that women eventually adapted well with respect to grief but a substantial number continued to demonstrate pathological scores for post-traumatic stress over 5 years. Significant risk factors for poorer outcomes were a lower level of formal education and of perceived lack of partner support. There is evidence to support the hypothesis that women with a higher level of formal education use more effective coping strategies (Huizink et al. 2002). However, the researchers caution that recollection of partner support may be influenced by current psychological well-being and as such may be a consequence rather than a cause of well-being (Korenromp et al. 2005). An association between higher gestational age and level of distress persisted, consistent with findings described earlier by Davies and colleagues. Women with a viable fetal abnormality experienced more long-term doubt and grief than those with a non-viable one. Further, 8–10% of female participants reported regret and doubt about their decision to terminate the pregnancy and these same women reported higher levels of post-traumatic stress (Korenromp et al. 2005).

In her story, the author reveals the deep sorrow, confusion and despair that she, her husband, and parents experienced as they embarked on the termination of their much welcomed son and grandson, Eli (Anonymous 2008). Her moving story conveys the heartache and trauma of the decision and its consequences, echoing the research findings that convey the significant long-

term adverse outcomes of choosing to terminate a desired pregnancy. Although she is highly educated, intimately aware of the circumstances as a genetic counselor and seemed to have a supportive and involved husband and parents experiencing the grief and trauma along with her, she did have the risk factors of being farther along in her pregnancy and in carrying a fetus with a potentially viable fetal abnormality.

The author chooses not to convey the brain abnormality that was found in Eli and defers getting into details about the final test results. As a reader, one suspects this may be due to ambiguity in the implications of the findings. Many abnormalities identified during development are difficult to predict and leave the parents grappling with layers of uncertainty and an unknown future. As the research findings suggest, the potential for viability is associated with more doubt and decisional regret. The author conveys residual uncertainty about the decision she and her husband made. Their ambiguity has likely added to their distress making it more difficult to adapt to their loss. Yet she has clearly made progress in two years time as she describes looking hopefully into her daughter's eyes towards a brighter future.

The author shares the many efforts she and her husband made, activities they participated in and rituals they developed to heal, desperate to find relief from the pain. She learns for herself the non-linear pattern of grief and the way the pain can come soaring back to blindsides her. In her recovery, she experiences the inability of certain colleagues to approach her and discuss her distress. At least some of these colleagues were health care providers and it is startling and upsetting that they cannot care for a colleague as they would care for a patient or client. It reminds us of the value in being able to take our counseling skills beyond the clinic and into our collegial relationships. When someone close to us experiences an unexpected significant loss, it serves to remind us all how vulnerable we are. To protect ourselves, we avoid the reminder and in doing so we deny a colleague our deserved love and support. The colleagues who were able to reach out to the author at her greatest times of need remind us to be strong in the face of adversity and to act as compassionate counselors regardless how threatening the circumstances may feel (Kessler 1999).

The author's journey and the research findings reviewed in this commentary teach us or remind us of the important role that genetic counselors can play in helping clients make difficult decisions and adapt to the consequences of those decisions over the long-term. Clearly, helping clients adapt to the decision to terminate a pregnancy goes far beyond arriving at and carrying out the decision. This decision is traumatizing and life altering. Genetic counselors can help clients recognize that their loss parallels any perinatal loss and that their grief is likely to be sustained over time. They can help them to identify coping strategies most effective at managing their distress. Interventions that have been found to help parents heal subsequent to a perinatal loss, including holding and seeing the baby, memorializing the baby's brief life, writing or journaling, reading, talking to others, learning about resources, and searching for ways one has gained personal strength or strength as a couple in enduring the loss together.

Gordon and colleagues report on the use of a facilitated shared experience group for women and their partners following termination for fetal abnormality (Gordon et al. 2007). Participants overwhelmingly endorsed it as the most beneficial format for addressing their distress and recovery. Genetic counselors have facilitated support groups or educational groups for those who have terminated a pregnancy but none have reported structured interventions or formal evaluation (Heimler 1990; Suslak et al. 1995). Given the more complex and protracted grief reactions reported in the case of terminations, the safety of the presence of others who are unlikely to judge you for your decision and highly likely to share your residual feelings of guilt or shame offers an opportunity for feeling less alone and vulnerable. Genetic counselors working in regions where such groups are not available could use their skills to initiate and

facilitate these group meetings. Studies of their structure and outcomes would help to further evaluate the usefulness of such efforts.

Many women were found to have psychiatric symptoms and post-traumatic stress symptoms years following termination of pregnancy. Genetic counselors should be routinely assessing the psychological status of couples post-termination and generously referring to psychiatrists and psychologists when symptoms exceed usual grief reactions. In order to make appropriate referrals, genetic counselors should maintain long-term contact with clients who have terminated their pregnancies, even if only by telephone. This offers an opportunity to reassess how clients are adapting over time. Data from long-term studies suggests that symptoms do not promptly abate and that many individuals experiencing the trauma of termination due to fetal abnormality would benefit from psychological counseling.

Overall, The author gives pause for thoughtful assessment of our work as genetic counselors. How do we best help our clients to make such traumatizing decisions? How do we best help them to live with the consequences of their decision over time? How can we develop effective practices for providing long-term support to couples who have terminated pregnancies? How can we overcome our own fears and feelings of inadequacy to reach out to colleagues in times of need? The author also gives us pause for thoughtful assessment of our own lives. How do we accomplish due diligence in appreciating our own good fortune if we have escaped the risk each of us faces to have a child with a birth abnormality? Thanks to the author for facilitating professional and self-reflection.

Acknowledgements

The writing of this manuscript was supported in part by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health. The author would like to thank Colleen Brown, Julie Cohen and Amanda Rowe for their assistance with references for this commentary, Gillian Hooker for editorial suggestions and the author for her courage.

References

- Adler NE, David HP. Psychological factors in abortion. A review. *American Psychologist* 1992;47(10): 1194–1204. [PubMed: 1443858]
- Anonymous. My story: A genetic counselor's journey from provider to patient. *Journal of Genetic Counseling*. 2008this issue
- Beatty PA. Physician as patient: Lessons to learn. *Annals Inter Med* 2004;141:404–405.
- Dallaire L, Lortie G, Des Rochers M, Clermont R, Vachon C. Parental reaction and adaptability to the prenatal diagnosis of fetal defect or genetic disease leading to pregnancy interruption. *Prenatal Diagnosis* 1995;15(3):249–259. [PubMed: 7784383]
- Davies V, Gledhill J, McFadyen A, Whitlow B, Economides D. Psychological outcome in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: a pilot study. *Ultrasound in Obstetrics & Gynecology* 2205;25(4):389–392. [PubMed: 15791695]
- Elder SH, Laurence KM. The impact of supportive intervention after second trimester termination of pregnancy for fetal abnormality. *Prenatal Diagnosis* 1991;11:47–54. [PubMed: 2027854]
- Geerinek-Vercammen CR, Kanhai HHH. Coping with termination of pregnancy for fetal abnormality in a supportive environment. *Prenatal Diagnosis* 2003;23:543–548. [PubMed: 12868079]
- Gordon L, Thornton A, Lewis S, Wake S, Sahhar M. An evaluation of a shared environment group for women and their support persons following prenatal diagnosis and termination for a fetal abnormality. *Prenatal Diagnosis* 2007;27:835–839. [PubMed: 17600863]
- Guttmacher A. Twenty lessons from the heart of medicine. *Journal of the American Medical Association* 2000;284:1486–1487. [PubMed: 11000619]

- Harris A. Supportive counseling before and after elective pregnancy termination. *Journal of Midwifery & Women's Health* 2004;49:105–112.
- Heimler A. Group counseling for couples who have terminated a pregnancy following prenatal diagnosis of a fetal abnormality. Strategies in genetic counseling, reproductive genetics and technologies. *Journal of the American Medical Association* 1990;26(3):161–167.
- Horowitz MJ, Siegal B, Holen A, Bonanno GA, Milbrath C, Stinson CH. Diagnostic criteria for complicated grief disorder. *American Journal of Psychiatry* 1997;154(7):904–910. [PubMed: 9210739]
- Huizink AC, de Medina PG, Mulder EJ, Visser GH, Buitelaar JK. Coping in normal pregnancy. *Ann Behav Med* 2002;24:132–140. [PubMed: 12054318]
- Hunfield JA, Wladimiroff JW, Passchier J. Pregnancy termination, perceived control and perinatal grief. *Psychological Reports* 1994;74:217–218. [PubMed: 8153215]
- Iles S, Gath D. Psychiatric outcome of termination of pregnancy for foetal abnormality. *Psychol Med* 1993;23:407–413. [PubMed: 8332657]
- Kersting A, Dorsch M, Kreulich C, Reutemann M, Ohrmann P, Baez E, Aroit V. Trauma and grief 2–7 years after termination of pregnancy because of fetal anomalies—a pilot study. *Journal of Psychosomatic Obstetrics and Gynaecology* 2005;26(1):9–14. [PubMed: 15962717]
- Kersting A, Kroker K, Steinhard J, Lüdtorf K, Wesselmann U, Ohrmann P, et al. Complicated grief after traumatic loss: a 14-month follow up study. *European Archives of Psychiatry and Clinical Neuroscience* 2007;257(8):437–43. [PubMed: 17629729]
- Kessler S. Psychological aspects of genetic counseling. XIII. Empathy and decency. *Journal of Genetic Counseling* 1999;8:333–344.
- Klitzman R. Improving education on doctor-patient relationships and communication: lessons from doctors who become patients. *Academic Medicine* 2006;81(5):447–453. [PubMed: 16639199]
- Korenromp MJ, Page-Christiaens GC, van den Bout J, Mulder EJ, Hunfeld JA, Bilardo CM, et al. Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenatal Diagnosis* 2005;25:253–260. [PubMed: 15791682]
- Korenromp MJ, Page-Christiaens GC, van den Bout J, Mulder EJ, Hunfeld JA, Potters CM, et al. A prospective study on parental coping four months after termination of pregnancy for fetal anomalies. *Prenatal Diagnosis* 2007;27:709–716. [PubMed: 17533631]
- McCoy JLM. Pregnancy interrupted: loss of a desired pregnancy after diagnosis of fetal anomaly. *Journal of Psychosomatic Obstetrics and Gynaecology* 2007;28(1):37–48. [PubMed: 17454512]
- McKevitt C, Morgan M. Illness doesn't belong to us. *J Royal Soc Med* 1997;20:491–495.
- Salvesen KA, Oyen L, Schmidt N, Malt UF, Eik-Nes SH. Comparison of long-term psychological responses of women after pregnancy termination due to fetal anomalies and after perinatal loss. *Ultrasound in Obstetrics & Gynecology* 1997;9:80–85. [PubMed: 9132260]
- Sandelowski M, Barroso J. The travesty of choosing after positive prenatal diagnosis. *Journal of Obstetric, Gynecologic, and Neonatal Nursing* 2005;34(3):307–318.
- Suslak L, Scherer A, Rodriguez G. A support group for couples who have terminated a pregnancy after prenatal diagnosis: recurrent themes and observations. *Journal of Genetic Counseling* 1995;4(3):169–178.
- White-Van Mourik MC, Connor JM, Ferguson-Smith MA. The psychological sequelae of a second trimester termination of pregnancy for fetal abnormality. *Prenatal Diagnosis* 1992;12:189–204. [PubMed: 1589421]
- Zeanah CH, Dailey JV, Rosenblatt MJ, Saller DN. Do women grieve after terminating pregnancies because of fetal anomalies? A controlled investigation. *Obstetrics & Gynecology* 1993;82(2):270–275. [PubMed: 8336876]