



NEWS, VIEWS & COMMENTS

Organ Donation: A Twin-Based Perspective / Research Reviews / Media Coverage

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Monozygotic cotwins are ideal organ donors for one another due to their genetic identity. The present report treats this topic differently, from the perspective of a monozygotic twin who donated her deceased twin sister's organs following her sister's untimely death. This discussion is followed by reviews of recent research concerning increased twinning rates in the United States, availability of informative kinship pedigrees, and twin discordance for physical activities. Noteworthy news items include ethical issues surrounding conjoined twin separation, a genomic discovery for diseased twins, China's One-Child Policy, a striking *New Yorker Magazine* cartoon, and twin delivery complications.

Organ Donation: A Twin-Based Perspective

Monozygotic cotwins are ideal organ donors for one another due to their genetic identity. In fact, the first successful kidney transplant took place between identical twins Ronald and Richard Herrick in 1954. The present report approaches this topic differently — it considers the perspective of a monozygotic (MZ) twin who donated her deceased twin sister's organs following her sister's untimely death from a brain hemorrhage at 35 years of age.

MZ twins Shelby and Shannon Miller were born 37 years ago to Donald and Paula Miller of Castaway Cove, Florida. Photographs of the twins (Figure 1 and 2) show their striking physical similarity, often considered a hallmark of identical twinning. The sisters, always close, attended college together, co-created two companies, and developed a fashion line called Shannon Britt shoes.

Both twins were prone to migraine headaches, but brain scans revealed no physical abnormalities in either one. Several European and Australian twin studies have found genetic influence on migraine, although two American studies failed to find this effect (see Ziegler, Hur, Bouchard, Hassanein, & Barter, 1998, for a review). A subsequent study by Ziegler et al. (1998), using reared-together female twins from Kansas and reared-apart female twins from the Minnesota Study of Twins Reared Apart (MISTRA), estimated that 50% of the variance in

migraine susceptibility could be explained by genetic factors, with nonshared environmental factors plus measurement error explaining the rest. It is also worth noting that the well-known 'Jim twins', who launched MISTRA in 1979, both suffered from a similar mixed headache syndrome from an early age (Segal, in press).

Shannon delivered her second child on August 5, 2009, with no complications. However, one week later she developed a severe migraine headache that did not respond to her usual medication. Shelby brought her sister to the hospital, at which time she showed an unusually high blood pressure reading for no apparent reason. An hour-and-a-half later, Shannon began having seizures, became paralyzed on her left side, and grew unconscious. She passed away from massive bleeding of the brain. Shelby immediately requested that the organ transplant team be contacted.

Organ donation was familiar to these twins, having had an uncle who lived for 11 years following a heart trans-

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FIGURE 1
MZ twins Shelby and Shannon Miller, at age 18 months.



FIGURE 2
MZ twins Shelby and Shannon Miller, at age 33.

plant. Aside from her migraines, Shannon was young and very healthy, so was able to donate all of her major organs, in addition to bone marrow and skin. It is believed that she saved or improved the lives of hundreds of people. Shelby and her family have met the man who received her sister's heart, and it was gratifying. 'That was such an amazing moment, to hear her heart again giving life. I was so proud to be her twin.'

In the process of arranging the organ donation, Shelby learned that there was professionally little attention to twins, in the sense that available information and support applied mostly to parents, children, and nontwin siblings donating organs to their family members. There was virtually nothing concerning surviving twins donating their cotwin's organs to unrelated individuals; staff at Shelby's local organization indicated that they were unaware of such an occurrence. Shelby provided them with information about twins and her contact number, and one week later learned that a second twin had just made the same

decision as she. Whether or not other such cases exist is uncertain; Internet searches I conducted did not identify cases like Shelby's.

In July 2011, the Miller family was honored by the National Organ Donation Ceremony, in Washington, DC. However, a twin-based approach to organ donation from the perspective of the surviving twin is still absent. 'Going to local organ donation meetings I found a void in twin recognition. I am in the process of trying to get it acknowledged.' Shelby's comment should be taken seriously, given my experience as director of an ongoing adult twin loss study and expert witness in court cases involving the wrongful death of a twin. Specifically, surviving twins often engage in activities designed to keep their deceased cotwin's memory alive, including writing a book, establishing a foundation, and speaking publicly. Organ donation, while limited to young, healthy individuals, is an option that Shelby hopes to make more widely known to surviving twins and their families.

Research Reviews

Increased US Twinning Rates

The latest report from the Center for Disease Control indicated a US twinning rate of 1 in 30 births (Martin, Hamilton, & Osterman, 2012; Stobbe, 2012). This figure for 2009 reflects a marked increase over the rate of 1 in

53 births reported in 1980 (i.e., 76%, from 18.9 to 33.3 births per 1,000). The greatest increase occurred among women over the age of 40 seeking reproductive assistance, because they are more likely than younger women to receive two embryos rather than one. Twinning rates

rose for women from Caucasian, African-American, and Hispanic backgrounds, but the increase was not uniform. The rates doubled for Caucasian women, increased by half for African-American women, and increased by about one-third for Hispanic women.

Reasons for the increased twinning rates include delayed child-bearing, responsible for approximately one-third of the change, and fertility treatments, responsible for approximately two-thirds of the change. Access to fertility treatments is a likely explanation for the dramatic increase in births among Caucasian mothers.

The elevated twinning rates have both positive and negative aspects. On the positive side, childless couples are able to have the families they desire. On the negative side, multiple births are high-risk pregnancies, and twins are more likely to experience adverse physical effects than singletons. The original report is available at <http://www.cdc.gov/nchs/data/databriefs/db80.pdf>

Kinship Pedigrees

Pedigrees (family trees) are indispensable tools for professionals working in a variety of fields, especially medical genetics, anthropology, and forensic medicine. Pedigrees are also of interest to individuals charting their family histories or searching for missing relatives. A comprehensive review of the different types of pedigrees, including a detailed glossary and charts depicting genetic relatedness among various kin, will be of interest to researchers working with twins (Mills, 2005). A discussion of complex relationships begins with MZ twins. It is noted that when such twins marry the same man or woman in succession, their children are genetically full siblings, and that when MZ twins marry different spouses their children are genetic half-siblings. These unusual relationships are well-known to twin researchers.

Interestingly, it is also noted that MZ twins, due to their genetic identity, are considered '0 degree' relatives. This seems incongruous at first, because MZ twins share 100% of their genes. However, it makes sense, because parent-child and

sibling pairs (genetic coefficient = .50) are considered first-degree relatives, aunts/uncles–nieces/nephews and half-siblings (genetic coefficient = .25) are considered second-degree relatives, first cousins (genetic coefficient = .125) are considered third-degree relatives, and first cousins once removed (genetic coefficient = .0625) are considered fourth-degree relatives, and so forth.

Body and Bone Mass

The mechanisms by which lean body mass are maintained remain largely unknown, but advanced metabolic methods have facilitated the study of relevant gene expression, cell signaling and tissue protein turnover (Rennie, 2012). Associations between different lifestyles (diet and exercise) and body musculature can be striking at the phenotypic level, especially in the case of MZ twins. An informative pair of pictures shows MZ male twins, Otto and Ewald, whose different athletic training programs in distance running and field events led to their extremely different muscle contours. Pictured from the front and the back at age 23 years, Ewald is clearly the broader and more robust of the two. University of Nottingham scientist, Michael Rennie, who authored the article asserted that 'human body size and composition are as much a matter of environment as of natural endowment, with each having about 50% influence' (p. 428).

The links between lifestyle and body composition were also pursued in a longitudinal twin study of physical activity and high-risk fat by researchers in Finland (Leskinen et al., 2009). A 32-year follow-up assessment of 7 MZ twin pairs and 9 DZ twin pairs discordant for physical activity revealed that inactive twins had a 50% higher visceral fat area, a 170% higher liver fat score, and a 54% higher intramuscular fat area. It was concluded that regular physical activity is a key factor in preventing fat accumulation, even after controlling for genetic risk and rearing environment. A picture (magnetic resonance image) comparing one set of cotwins' high-risk fat accumulation is revealing.

Media Coverage

Conjoined Twin Separation

Conjoined twin separations are often controversial, given that a physically impaired twin may be sacrificed to keep his or her healthier cotwin alive. Another difficult scenario involves dividing the twins with the knowledge that each will lose various functions or body parts. Twin separations are often discussed in the media, further complicating choices for families and physicians. A recent article in *Practical Ethics* by Romanian-Australian philosopher and

bioethicist Julian Savulescu explores some of these issues in other ways (Savulescu, 2011). His contribution was, no doubt, inspired by the 2011 birth of Brazilian conjoined male twins born with separate brains and spinal columns, but who shared their heart, lungs, liver, and other organs (BBC News, 2011).

Savulescu argues that if prenatal conjoined twin separations were possible, they would not differ from selective termination of multiple embryos. He believes that separation

is ethically justified if the survival chances of one twin are low and that separation would greatly assist the cotwin. He also claims that such separations are infanticide and that in such cases people need to acknowledge the fact that one twin is being sacrificed for the benefit of the other. He notes further that such situations are not dealt with adequately by current legislation. Savulescu also discusses the possibility of disagreement between adult conjoined twins over the decision to separate, indicating, 'one should err on the side of life.' He noted that sacrificing one twin for the other can only occur in the case of infants who are incapable of making such decisions. Savelescu's statements will most likely inspire further dialogue and discussion, due to the highly emotional nature of this topic.

The delivery, care, and management of conjoined twins have improved in recent years. Such changes will likely raise new ethical and practical issues that cannot be foreseen. Savulescu concludes by urging greater appreciation for human variation and greater consideration of the interests of both twins in decisions surrounding separation.

Genomic Breakthrough for Twins

Twelve-year-old, opposite-sex twins, Noah and Alexis Beery, had been diagnosed with cerebral palsy at the age of 2 years. Alexis, the more severely affected twin, showed muscle weakness and fatigue that worsened continually. When the twins were nearly 6 years old, their mother learned about dystonia, caused by a deficiency in the nervous system messenger, dopamine. Dystonia is treated with the drug Sinemet. When Alexis received this medication, her symptoms abated, but after several months of treatment both twins' symptoms recurred.

Events leading to the twins' medical breakthrough began in 2008 when their father, chief information officer at US Airways Group Inc., was offered a position at Invitrogen (later renamed Life Technologies). Beery and his wife were told that Invitrogen planned to purchase a DNA sequencing company, with the potential to identify defective genes in children within weeks or months. Beery accepted the job, and in 2009 attended a presentation by Scripps Research Institute researcher, Eric Topol, on the topic of genomic sequencing and disease. With the cooperation of Baylor University scientists and Life Technologies, the twins' genomes were sequenced. It was discovered that, in addition to dopamine deficiency, both twins had a second mutation that interfered with serotonin production. Following serotonin replacement, the twins' improvement was dramatic.

China's One-Child Policy

A wealthy Chinese couple is at the center of national turmoil in the wake of their country's one-child policy (Kaiman, 2012). It was discovered that their finances enabled them to give birth to eight children via assisted

reproductive technology — two sets of triplets and one set of twins that included four boys and four girls. The cost was \$158,000. The unfairness of the situation, namely that wealthy couples can afford to circumvent national policy, is the issue driving the widespread response.

Chinese hospitals have been forbidden to conduct gestational surrogacy procedures since 2001, but surrogacy agencies have proliferated nevertheless. It has been estimated that 25,000 Chinese children were born during the last 30 years using surrogate mothers. And despite the highly charged reactions to the births of the twins and triplets, it is worth noting that twins are celebrated in China, as evidenced by annual national festivals.

New Yorker Magazine Cartoon

A striking cartoon appeared in the January 16, 2012 issue of the *New Yorker Magazine*. It depicts a man lying between two identical-looking women, with a caption to the effect that he would like to start seeing other twins. The scene suggests that (1) MZ twins find the same potential mate sexually attractive, and (2) nontwins married to MZ twins find their spouse's cotwin sexually attractive. However, these effects may not be as strong as the cartoon artist supposed. In a twin study of human mating preferences, Lykken and Tellegen (1993) found that human mating is adventitious, explaining why, despite their many behavioral similarities, (1) MZ twins were not necessarily attracted to their cotwin's partner, with 40% disliking the partner when the choice was made, and (2) just 13% of 131 men married to an identical twin and 2% of women married to an identical twin were attracted to their spouses cotwin. In contrast, Rushton and Bons (2005) found that the friends and spouses of MZ twins were more alike behaviorally than those of DZ twins.

These conflicting findings will need to be reconciled with the MZ twin couples who marry one another, although it difficult to know how frequently this type of marriage occurs (Segal, 2007). Such couples enjoy this arrangement because their spouses understand the closeness of their relationship with the cotwin. At the same time, the individual twins claim that they are not attracted to their brother's or sister's spouse. It seems that subtle differences in appearance and behavior have a significant impact on the selection of mates.

Delivery Complications

Singer Michal Laura Friedman, known as Michal the Singer, was a regular performer at Joe's Pub in New York City's East Village. Friedman passed away tragically in November 2011, at the age of 44 years, from surgical complications following the Caesarean section delivery of healthy opposite-sex twins (DNAinfo.com, 2011). She and her husband had been trying to have a family for 7

years. The specific circumstances of her death were not reported, but the event underlines the increased maternal risk posed by multiple birth deliveries.

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