## WOMBMATES



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Every year in Twinsburg, Ohio, thousands of twins gather for the Twins Day Festival. It is here that multiples (twins or triplets) are able to share stories, participate in voluntary research studies and celebrate what it means to be a multiple.

This festival normalizes being a multiple in a way that everyday life can never capture. As a twin myself, I cannot count the number of times someone has asked me if I like being a twin (I can not say that I have ever had the experience of not being one), if I can feel my sister's pain (which would be unpleasant) or if we have the same personality (no, we happen to be two different people). These questions, and many more, are all ones that every multiple has been faced with at one time or another.

Despite being separate people, multiples--especially twins as they are more likely to be identical--are stereotyped and fetishized in the media. As a result, twins are seen as a

novelty and even, at times, less than human. There have been many instances recorded throughout the 20th century alone of unethical twin studies. From Nazi experiments during World War II to nature versus nurture adoption experiements in the 1960s, twins have

been studied for the purpose of science without regard for their natural human rights.

From my perspective of being a twin, the media does nothing to dispel these stereotypes--in fact they perpetuate them through books and television. Award-winning

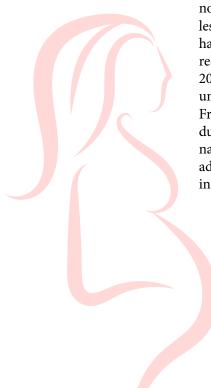
shows such as *The Game of Thrones* by George R. R. Martin and authors such as Donna Tart play into the stereotype of fetishizing twins--perverting what it means to have a built in best friend, by writing about twins in a sexual way.

In addition, books such as *The Lies of Locke Lamora* and *Harry Potter* typecast twins as the same people and lack distinctive personalities. They use twins as the "token characters" or as plot devices. Singletons (those who are not multiples) seem to have a fixation with twins and a tendency to portray them more as objects than people, which comes from a fascination with twins that originated from conducting unethical experiments.

A glaring example of unethical testing on twins are the experiments conducted by Nazis during World War II. Dr. Josef Mengele was a Nazi doctor in charge of experiments in the concentration camps. Whenever a set of twins entered one of the camps, he had them separated from the other prisoners so that he could study them. These experiments often included studying every aspect of identical twins to compare their differences, injecting both siblings with various diseases to compare their reactions and, finally, killing the set of twins at the same time so that they could be dissected and studied postmortem. Documented by BBC and the Nazis themselves, these experiments, like everything done by the Nazis, were glaringly unethical to the extreme.

Mengele was known to have a special interest in twins and a letter from him to a friend was published in a 1985 New York Times article saying, "It would be a sin, a crime . . . and irresponsible not to utilize the possibilities that Auschwitz had for twin research," and that "there would never be another chance like it." The idea that there were scientists who were just waiting for the chance to experiment on twins is disturbing to say the least, and exposes the cultural fascination with them.

Unethical testing with twins did not end with Mengele's experiments for the Nazis in Auschwitz. In the 1960s, Yale researcher Peter Neubauer began conducting twin studies on multiples put up for adoption. When the siblings were adopted, the families were not told that their adopted child was a multiple. Over the course of these



children's lives, Neubauer and his research team studied the effects of nature versus nurture as identical twins grew up separated. They wanted to see if genetics played a greater role in personality than that of home environment. The families were led to believe that the visits from the researchers were routine visits from the adoption agency. The multiples did not know they were being studied. This experiment enters into an even more gray area of ethics.

Some argue that if the twins were put up for adoption, they would most likely have been separated regardless, and so it is not unethical to study the results of this separation. The question I pose, however, is whether or not it is ethical to study the growth of twins without their consent or the consent of their families. Though consent in scientific studies was hardly necessary in the 1960s, it set a precedent for future studies involving twins.

The ideas defending unethical twin studies still persist today, though circumstances have become significantly less extreme. It is possible to currently find peer-reviewed articles published in academic journals that defend the adoption experiments conducted by Neubauer. In addition, Yale, the institute Neubauer was connected to at the time, has sealed his research files until 2065. Even the eight sets of twins and the set of triplets who were the unwilling subjects of the study are unable to view their own files, despite their demands to do so. Because of this, no one outside of those who reviewed the files before they were sealed know the full extent of Neubauer's experiments. Without the details being released, how can it be prevented in the future?

And these studies need to be prevented in the future. As a twin, I can say that the article defending this study was hard to read. I have never felt more aware of the fascination that surrounds twins, like my sister and me, than when I was reading about Mengele and Neubauer's experiments. Reading how multiples are used and manipulated in the name of science disgusted me. It was equally disturbing to see articles defending these

experiments. Since twins offer a perfect, built-in control group, there need to be specific regulations to prevent researchers from abusing or taking advantage of them.

Yes, there is probably a lot to be learned about human behavior by studying twins, but that information is not worth the cost. Instead, twin studies should be conducted under voluntary, consensual conditions. Twins should not be purposefully separated at birth with the sole intention of being studied, and the festival at Twinsburg, Ohio gives a perfect example of how being a multiple should be studied through volunteer efforts.

Being a twin should be celebrated, not used for science. The research conducted on multiples should be to the benefit of those being observed, not just to the observer. The Twins Day Festival in Twinsburg, Ohio can be used as a model for fostering communication about what it means to be a twin and how twins are, first and foremost, human beings.

Someday I hope that my sister and I will be able to attend this festival and be surrounded by thousands of people who understand the difference between clones and twins, who also roll their eyes when people ask if they can read each other's thoughts and who want to participate in an ethical understanding of the phenomenon in which they are included.

