

## The Case of the Bijani Twins: Why the doctors should have said “no”

*Arthur Schafer*

This much is certain. The failed operation to separate the Bijani sisters is guaranteed of immortality through endless discussion in bioethics textbooks and university classrooms. Future generations of doctors and ethicists will cut their philosophical eye teeth in debates about whether it was morally right for Dr. Keith Goh - and his team of neurosurgeons, plastic surgeons, anaesthetists and specialized nurses – to attempt this risky procedure. The ethical concerns are many. Resolving them won't be easy.

There is unanimous medical consensus that the operation was “risky”. Everyone also agrees that before undertaking life-threatening surgery, it is morally necessary that doctors obtain the *informed* consent of their patients. Indeed, given the very high risk that one or both of the twins would die and the further risk of serious brain-impairment even should they survive, their consent needed to be based upon a realistic assessment of all the likely benefits and harms. Any patient faced with such a medically dangerous choice would require extensive assistance both to understand the complex information and reasonably to balance hopes against fears.

The Bijani twins shopped worldwide in an effort to find a neuro-surgeon who would agree to separate their conjoined brains. Until they encountered Singapore neuro-surgeon Dr. Keith Goh, they did not find a single doctor willing to undertake this procedure. As early as 1988, renowned German neuro-surgeon, Dr. Madjid Samii, refused their request to operate, on the grounds that “it was impossible to do the surgery”.

The Raffles hospital, Singapore, where the operation took place, claimed that recent scientific developments made the operation technically feasible. American neuro-surgeon Dr. Benjamin Carson, a member of Dr. Goh's team, estimated that each sister had a fifty-fifty chance of survival. Dr. Samii, by contrast, considered the operation impossible in 1988 and still impossible in 2003, and he therefore judged it foolhardy to proceed. Alas, those who foretold disaster turned out to be correct.

How to account for these widely discrepant assessments of the likelihood of success? The procedure has been carried out successfully in infants and children, but their skulls are softer and their brains and circulatory systems are less intertwined than is the case with adults. Because of this, any estimate of the survival odds for the Bijani twins was bound to be more guess-work than science. The fact that Dr. Goh's team failed doesn't *prove* that their assessment of the odds of success was incompetent; but they clearly underestimated the severity of the challenge they faced. They can also be criticized ethically for their decision to proceed with the operation even after they ran into serious difficulty. At that point, ordinary prudence would have dictated a halt. It seems to be the case that when doctors aim for major medical breakthroughs, their hope for international celebrity can sometimes skew their judgement.

As competent adults, Ladan and Laleh Bijani had the right to make risky choices with their own lives. When they approached Dr. Goh, they certainly knew that they were risking their lives. But there is an enormous difference between taking a gamble when the odds are fifty-fifty compared to gambling one's life when the odds of dying are closer to 100%. Thus, whether the sisters were truly able to give informed consent hinges on whether they understood the full magnitude of the risks they faced. It seems likely that they, like Drs. Goh and Carson, allowed their hopes for success to outweigh the cold hard realities with which they were faced.

Every competent adult patient has the right to make decisions which others may regard as wrong-headed or even foolish. But doctors are not simply handmaidens to their patients' wishes. Unlike merchants in the consumer marketplace, doctors have their own professional integrity to consider. Medical ethics requires that doctors not acquiesce to a patient's wishes unless the doctor agrees that the requested treatment is likely to be of benefit to the patient. If a patient demands an antibiotic for a viral infection, for example, an ethically conscientious physician would refuse because in this circumstance the antibiotic would not help the patient and might cause harm.

Medical treatments which pose high risks of death and/or brain impairment may sometimes be worth considering. When, say, high-risk treatment offers some hope of survival while non-treatment means certain death, then it would make sense to gamble on treatment. "What have you got to lose?" But the Bijani sisters were apparently healthy, and the life they were leading, while far from ideal, seemed in many ways to offer possibilities for fulfillment. Despite their conjoined skulls and fused circulatory systems, they were able to live in the community. They studied at university and acquired a law degree, gave dinner parties, enjoyed the company of friends. It seems sadly inappropriate, therefore, to say that they had nothing to lose. They had a lot to lose.

Nevertheless, they wanted, more than anything, to live normal lives. It is difficult not to sympathize with this desire. The fierce determination with which Ladan and Laleh pursued surgical separation is strong evidence that they found their conjoined condition to be highly oppressive. Everyone understands that living with another person entails compromise. But when two very different people are forced by nature to live as one person, the term "compromise" takes on an altogether different dimension.

The Bijani sisters diverged markedly in aspirations and personality. Ladan wanted to pursue a law career, Laleh wanted to be a journalist. Ladan preferred computer games, Laleh liked to pray. It's not easy to engage in prayerful activity when you are forced to sit at a computer screen while your sister is zapping aliens. Obviously, as conjoined twins, each was compelled to accept huge restrictions on her freedom, make difficult compromises, and accept the impossibility of marriage and children. Thus, their willingness to accept considerable risk in order to achieve some of the things that everyone else takes for granted is easy to understand. But did they understand that the operation they sought meant near-certain death? The answer to this key question remains unclear.

One final reflection. The total costs of this unprecedented operation approached a million dollars. In a part of the world where hundreds of thousands of children die from diarrhea, because they have no access to a mixture of clean water, sugar and salt, one has to ask: can one justify allocating so many scarce medical resources in such a hopeless cause? The plight of the Bijani sisters captured the imagination of the world. It made a brilliant media splash. Children dying *en masse* from dehydration don't make a similar impact. That probably says something unpleasant about us.

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