

APPENDIX 1

Sentences analysed in 'A Pandora's box of ethical paradoxes' (Text 1)

1. Had the Iranian conjoined twins, Ladan and Laleh Bijani, survived a successful separation the team of surgeons operating on them would now be drowning in international praise and accolades.
2. They might have even won the Nobel Prize for medicine for having successfully performed an extraordinary feat.
3. Unfortunately, the anticipated joy was never to be and sadness rues the bereaved.
4. The twins leave behind a grieving adopted father, himself a doctor, who was reportedly beset with misgivings having always believed that any operation to separate his daughters would be dangerous.
5. By all accounts the Bijani twins have been pursuing their dream of physical separation for years.
6. When they were 14, a medical examination in Germany disclosed that any surgical attempt to separate the twins joined at the skull would be more than likely kill them.
7. Hence the decision then by the doctor to not tamper with a physiological conundrum not easily solved.
8. However, a recent pre-surgery press conference clearly demonstrated that the twins were adamant about wanting a future separated: to be able to look at each other's face without the need for a mirror; to be able to achieve their individual ambitions apart, in different cities.

9. They were acutely aware of the very high risk they were taking and the real possibility of them not making it.
10. They stared death in the face and went ahead anyway.
11. If a chance of success did at all exist it was not for them both when, in fact, the possibility of survival for even one of them was slim indeed.
12. Yet, they signed away their lives willingly for what is obviously an impossible dream.
13. Shorn of any pretence of hope, the operation may be viewed, by some quarters especially, as at best, euthanasia.
14. A member of the surgical team has defended their decision to operate as a humanitarian act.
15. But, this is what medical practitioners accused of assisting suicides say in defense of their action, which is in direct contradiction of the Hippocratic Oath doctors take, one premised on a rather particular perception of life-that it is sacrosanct.
16. This is a perception arising out of a religious dictum subscribed to by the monotheistic tradition and most other religious traditions.
17. Life, under these belief systems, is entrusted to the individual who has no right to terminate it willfully before death overcomes it naturally.
18. Which makes the signing away of their lives by the twins, given the high risk of death, unacceptable.
19. In short, Ladan and Laleh Bijani, if they had been properly counselled of the risks had no right to gamble away their lives on very long odds.

20. Which, in turn, leaves the decision by the surgeons to perform the operation, with its attendant unacceptably high risk to life, questionable.
21. Why then the decision to operate?
22. There is a suggestion that pressure from the twins on the doctors may have been too great to resist.
23. The humanitarian argument would accommodate this possibility well.
24. For some reason, known only to the twins and maybe their doctors, a life conjoined was insufferable, hence their unrelenting search for a team of doctors that would undertake to relieve them of this unbearable burden.
25. They knew too that it would not be cheap.
26. Despite this they remained uncompromising to the end.
27. Thus the doctors in Singapore were persuaded that the risk is commensurate with the alleviation of suffering should a miracle be theirs to have.
28. A miracle, sadly, is unacceptable medical odds.
29. Advances in medical science may, too, have contributed to the over-optimism, which must have coloured the now most definitely unfortunate decision by both parties.
30. The desperation felt by the late Bijani twins was probably made more acute by the dazzling, state-of-the-art equipment available in this very modern hospital, a situation compounded by the near mythical quality that contemporary technology has acquired as a bestower of miracles.

31. Test-tube babies, cloning and stem cell technology are all examples of a future promising life-on-demand, accompanied by seductions of possible immortality.
32. Death is seemingly easy to cheat nowadays; making it a probable factor in misleading many medical decisions down the proverbial road to Emerald City, including this one made in the Lion City.
33. Should the possibility of normative values not be properly synchronised and a cultural gap actually did surface vis-à-vis the issue of respect for life; when for the sake of the general good two lives were risked after much scrutiny and consideration and all, not unlike the experience of the Middle Ages when live human specimens were cut open for the benefit of medical sciences; when no conceivable humanitarian reasons are imaginable to justify risking Ladan and Laleh's lives, some input was glaringly missing to enable an arm's length assessment of the feasibility of the undertaking.
34. Is the chase after quality of life reason enough to flirt with death?
35. Hindsight is undoubtedly a cruel facility that makes human folly more terrible than what it already is.
36. It is almost kinder not to pass judgement.
37. But, when all is said and done, a life is all that one has, a Divine gift, non-recognition of which fact leaves humanity bereft of meaning.
38. Therefore, a stand must be taken and a future reference be enabled.
39. A life is not to be trifled with.
40. The fate of two lives?

41. Certainly not where mere mortals can play God for, surely here even angels
fear to tread without especially good cause.

APPENDIX 2

Sentences analysed in 'Struggle to be free' (Text 2)

1. I was heading home on July 8 with one of my service canines after a visit to our friendly vet when I first heard the news over the radio.
2. Singapore Radio interrupted its broadcast just before 7 pm to bring in a live press conference from the medical team at the local Raffles Hospital.
3. The doctors who had tried to surgically separate the 29-year-old conjoined Iranian twins, Ladan and Laleh Bijani, who were fused together from birth in one skull but with separate functioning brains, solemnly and sorrowfully announced their failure in their mission – and that the girls had died in the Lion City as a result.
4. Like most Malaysians, I was devastated by the news.
5. I recall needing to drive myself around the block several times before I could finally come to terms and comprehend the depths of what had happened.
6. Although we all knew that the never-before-attempted-surgery had only 50-50 chance of working out, like most of my friends, we were somehow only expecting and praying for nothing but the best to happen for the Bijanis.
7. The woeful news of the women's deaths first brought on lots of tributes and praise for not only the girls who were well-known in Iran for their courage and academic success, but even for the surgeons who performed the operation.
8. Then slowly came the blame and shame.

9. One of the most scathing of these was from the Bijani's adoptive father, Alireza Safaian, a doctor himself who had raised the girls.
10. There were also, upon hindsight, serious medical and ethical factors involved in the outcome of the twins' surgery.
11. The Bijani debate was also a hot issue in discussions on international disability chat rooms and newsgroups.
12. Some wondered if conjoined twins could be considered "disabled" at all, whilst others called it a "spectacular disability".
13. Whilst almost everyone appreciated and respected the struggle that conjoined twins had to go through to try to be independent of each other, they were, however, more concerned about disabled persons being treated as "freaks" of society where they needed to be studied by the medical world.
14. There were other more blunt questions and comments: is death considered a "better" option than life for conjoined twins and severely disabled people?
15. Or could situations like that of the Bijanis and others be a subtle form of eugenics (the race to create a better race) at play, or perhaps plain scientific research being pushed to the limits to try and eliminate the existence of disabled people by trying to "correct" those whom we perceive as having "birth defects"?
16. Even if disabled people request for surgery, do they have access to relevant advisors, say, other disabled people who would be in the best position to proffer the right kind of counsel?
17. All this brings to mind my own extraordinary beginnings.

18. I was born with spina bifida, (a congenital condition of the spine) which showed up as a lump on my lower back that was the size of a small marble when everyone first noticed it.
19. The doctors at the time wanted to surgically snip it off to "improve my fate" but warned that I would only have a 50-50 chance of survival.
20. They also said that with my disabilities and possibly newer ones that could come later on, my life really wouldn't amount to much.
21. My family vehemently refused (thank God!) and I still have the lump with me today except that it is about the size of a football now that's nicely concealed by the back of my wheelchair.
22. Imagine for a moment the unthinkable if my parents had listened to the doctors and gone ahead with the surgery.
23. Gosh there just might not be a *Wheel Power* column today!

A Pandora's box of ethical paradoxes

HAD the Iranian conjoined twins, Ladan and Laleh Bijani, survived a successful separation the team of surgeons operating on them would now be drowning in international praise and accolades. They might have even won the Nobel Prize for medicine for having successfully performed an extraordinary feat. Unfortunately, the anticipated joy was

never to be and sadness rives the bereaved. The twins leave behind a grieving adopted father, himself a doctor, who was reportedly beset with misgivings having always believed that any operation to separate his daughters would be dangerous.

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However, a recent pre-surgery press conference clearly demonstrated that the twins were adamant about wanting a future separated: to be able to look at each other's face without the need for a mirror; to be able to achieve their individual ambitions apart, in different cities. They were acutely aware of the very high risk they were taking and the real possibility of them not making it. They stared death in the face and went ahead anyway.

If a chance of success did at all exist it was not for them both when, in fact, the possibility of survival for even one of them was slim indeed. Yet, they signed away their lives willingly for what is obviously an impossible dream. Shorn of any pretence of hope, the operation may be viewed, by some quarters especially, as at best, euthanasia.

A member of the surgical team has defended their decision to operate as a humanitarian act. But, this is what medical practitioners accused of assisting suicides say in defence of their action, which is in direct contradiction of the Hippocratic Oath doctors take, one premised on a rather particular perception of life - that it is sacrosanct. This is a perception arising out of a religious dictum subscribed to by the monotheistic tradition and most other religious traditions. Life, under these belief

systems, is entrusted to the individual who has no right to terminate it willfully before death overcomes it naturally.

Which makes the signing away of their lives by the twins, given the high risk of death, unacceptable. In short, Ladan and Laleh Bijani, if they had been properly counselled of the risks had no right to gamble away their lives on very long odds.

Which, in turn, leaves the decision by the surgeons to perform the operation, with its attendant unacceptably high risk to life, questionable. Why then the decision to operate?

There is a suggestion that pressure from the twins on the doctors may have been too great to resist. The humanitarian argument would accommodate this possibility well. For some reason, known only to the twins and maybe their doctors, a life conjoined was insufferable, hence their unrelenting search for a team of doctors that would undertake to relieve them of this unbearable burden. They knew too that it would not be cheap. Despite this they remained uncompromising to the end. Thus the doctors in Singapore were persuaded that the risk is commensurate with the alleviation of suffering should a miracle be theirs to have. A miracle, sadly, is unacceptable medical odds.

Advances in medical science may, too, have contributed to the over-optimism, which must have coloured the now most definitely unfortunate decision by both parties. The desperation felt by the late Bijani twins was probably made more acute by the dazzling, state-of-the-art equipment available in this very modern hospital, a situation compounded by the near mythical quality that contemporary technology has acquired as a bestower of miracles. Test-tube babies, cloning and stem



cell technology are all examples of a future promising life-on-demand, accompanied by seductions of possible immortality. Death is seemingly easy to cheat nowadays; making it a probable factor in misleading many medical decisions down the proverbial road to Emerald City, including this one made in the Lion City.

That Singapore's *Straits Times* can be coldly surgical in writing that "Singapore will gain in international renown for its medical advances when the verdict of professional peers are in" signals a bravado, which were it part of the reason for the decision to operate, without a doubt, would make that decision unethical, notwithstanding the consent of the patients. Two lives were being risked and if there was even a whiff of the intention to build professional reputations or, for that matter, increasing the learning curve; something is sadly amiss with the ethical standards of the international medical community.

Should the possibility of normative values not be properly synchronised and a cultural gap actually did surface *vis-à-vis* the issue of respect for life; when for the sake of the general good two lives were risked after much scrutiny and consideration and all, not unlike the experience of the Middle Ages when live human specimens were cut open for the benefit of medical science; when no conceivable humanitarian reasons are imaginable to justify risking Ladan and Lalah's lives, some input was glaringly missing to enable an arm's length assessment of the feasibility of the undertaking. Is the chase after quality of life reason enough to flirt with death?

Hindsight is undoubtedly a cruel facility that makes human folly more terrible than what it already is. It is almost kinder not to pass judgment. But, when all is said and done, a life is all that one has, a Divine gift, non-recognition of which fact leaves humanity bereft of meaning. Therefore, a stand must be taken and a future reference be enabled. A life is not to be trifled with. The fate of two lives? Certainly not where mere mortals can play God for, surely here even angels fear to tread without especially good cause.

The writer, a freelancer, is a former senior analyst at SIS, head of news and current affairs at Astro

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6 Lifestyle

Is death considered a 'better' option than life for conjoined twins and severely disabled people?

By ANTHONY THANASAYAN

I WAS heading home on July 8 with one of my service canines after a visit to our friendly vet when I first heard the news over the radio.

Singapore Radio interrupted its broadcast just before 7pm to bring in a live press conference from the medical team at the local Raffles Hospital.

The doctors who had tried to surgically separate the 29-year-old conjoined Iranian twins, Ladan and Laleh Bijani, who were fused together from birth in one skull but with separate functioning brains, solemnly and sorrowfully announced their failure in their mission - and that the girls had died in the Lion City as a result.

Like most Malaysians, I was devastated by the news.

I recall needing to drive myself around the block several times before I could finally come to terms and comprehend the depths of what had happened.

Although we all knew that the never-before-attempted-surgery had only a 50-50 chance of working out, like most of my friends, we were somehow only expecting and praying for nothing but the best to happen for the Bijanis.

The woeful news of the women's deaths first brought on lots of tributes and praise for not only the girls who were well-known in Iran for their courage and academic success,

Struggle to be free

but even for the surgeons who performed the operation. Then slowly came the blame and shame.

One of the most scathing of these was from the Bijani's adoptive father, Alireza Safalan, a doctor himself who had raised the girls.

"When they took them to Singapore, I knew they would bring back their bodies. They took them there and killed them," Alireza was reported to have said.

There were also, upon hindsight, serious medical and ethical factors involved in the outcome of the twins' surgery.

Dr Richard Nicholson, editor of the *Bulletin of Medical Ethics*, told BBC Online that in most cases the risk of death would be rated too high for doctors to proceed with surgery.

Dr Nicholson, however, conceded that imaging techniques were not sophisticated enough to allow doctors to know with precision how surgery would develop before they started.

"Doctors have a duty to act in the best interests of their patients, and in retrospect one is bound to conclude that maybe this surgery (Bijanís) was misguided," he said.



Conjoined Iranian twins, Ladan and Laleh Bijani, 29.

"These twins were not suffering from a life-threatening condition, and although there were many things wrong with the quality of their lives, they had coped for 29 years." Dr Nicholson added that he had concerns about the fact that it would have been impossible to brief each twin separately about the risks.

Thus it was possible that one twin could have pressured the other to go ahead against her will, he concluded.

The Bijani debate was also a hot issue in discussions on international disability chat rooms and newsgroups.

Some wondered if conjoined twins could be considered "disabled" at all, whilst others called it a "spectacular disability".

Whilst almost everyone appreciated and respected the struggle that conjoined twins had to go through to try to be independent of each other, they were, however, more concerned about disabled persons being treated as "freaks" of society where they needed to be studied by the medical world.

Sometimes society tends to go to extreme lengths to try and "fix" disability hoping that it will go away - instead of doing the right thing by facing up to a situation and offering societal support and total acceptance that people with disabilities need, said one disability expert.

There were other more blunt questions and comments: Is death considered a "better" option than life for conjoined twins and severely disabled people?

(Incidentally, some chums with disabilities confessed to me that given the chance, they would much rather go through life as a conjoined twin than to be blind or crippled as they are now.)

Or could situations like that of the Bijanis and others be a subtle form of eugenics (the race to create a better race) at play, or perhaps plain scientific research being pushed to the limits to try and eliminate the existence of disabled people by trying to "correct" those whom we perceive as having "birth defects"?

Even if disabled people request for surgery, do they have access to relevant advisors, say, other disabled people who would be in the best position to proffer the right kind of counsel?

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