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A Discussion of Ethical Issues in the Case of Baby Fae

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A Discussion of Ethical Issues in the Case of Baby Fae

Abstract

Medical professionals are presented with numerous ethical questions that need answering on an almost daily basis. In this paper, the story of Baby Fae is used as a vehicle to discuss ethical issues. This case highlights the core ethical question regarding the taking of an innocent animal's life to attempt to save the life of an innocent human. It has been more than twenty-six years since Baby Fae lived and died with a baboon heart keeping her blood flowing and her body alive. Presented in this paper are the facts, simply stated, regarding an historical event that had a profound effect upon medical history. Nurses played a role in it that other nurses can emulate: working professionally in the face of great opposition, retaining patient privacy rights, realizing that we cannot always have a vote about which side of a case we would like to be on, and functioning non-judgmentally as a patient advocate. It can be easy to laud or criticize an historical event; but, we do not live in history – we only hope to learn from it.

“Those who know what’s best for us must rise and save us from ourselves.”ⁱ But, who knows what is best for us when the definition of right and wrong is blurred? What is right and wrong when the meaning has yet to be defined and who gives one the authority to establish what is right and what is wrong? What if there are two perceived rights (or wrongs) and a decision must be made between the two? Now give this a moment of thought: is it right to do wrong in order to do right? Life can, and usually does, present us with problems that need more than a cursory inspection of a rule book or even an in-depth appraisal of a terrestrial guru’s faculties. Given a scenario already recorded in history, one may be glad he or she was not the person that had to come up with a decision that *now* is too easy to laud or criticize. Not everything that can be thought of has been thought of already. There are moments in time that create reasons for each of us to look inwardly and outwardly in order to determine that, perhaps, something needs to change – now how do we collectively move toward that end? The purpose of this work is to look back at such an event in recent history that did just that and learn about making ethical decisions. It is now time to take off the nursing shoes and, non-judgmentally, “walk a mile” in the shoes of others.

One evening in late 1984 in the high-desert city of Barstow, California a twenty-four-year-old woman, pregnant with her second child began to bleed vaginally. Still about two weeks short of her baby’s due date, she hurried to the local community hospital. Three hours later her baby daughter was born. Soon after delivery they knew something was wrong. The baby’s mother, Teresa Beauclair, was granted only a minute with her daughter before the nurses took the newborn out of the delivery room. A few hours later the baby was rushed by ambulance to Loma Linda University Medical Center

in Loma Linda, California. Soon after Ms. Beauclair's discharge from the Barstow hospital she drove to there to be with her daughter. "When I got there I never, ever, dreamed that I would be told that there was nothing that they could do to help her and that she was going to die," Ms. Beauclair recalled. "I remember being really upset and I said, 'You mean you can put a man on the moon; but, there's nothing you can do to help her,' and he (the Dr.) said 'no.'"ⁱⁱ The newborn was diagnosed with hypo-plastic left-heart syndrome (HLHS). This congenital condition results in left side of the heart being physically under-developed in its entirety. The left atrium, mitral valve, left ventricle, and aortic valve are all too small to pump sufficient blood to the brain, organs, and rest of the body. The body not only is deprived of oxygen and nutrients; but, the lungs and right-side of the heart become congested and begin to fail as well. Until the early 1980s, this diagnosis was fatal 100% of the time. The young mother was given a choice: 1) Let her baby die in the Loma Linda hospital, 2) let her die at the hospital in Barstow, or 3) let her die at home. After she "went outside and cried, and screamed, and threw a temper tantrum, basically,"ⁱⁱⁱ Ms. Beauclair chose the last option. Not wanting to have the memory of her daughter's passing where she lived, she checked into a motel in Barstow. There, for a couple of days, mother and baby bonded; Ms. Beauclair came to the conclusion that her daughter had the right to die at home.



A few days later, Ms. Beauclair called Loma Linda University Medical Center to report that the infant was becoming jaundiced. Dr. Dougals Deming, the perinatologist/neonatologist that diagnosed the baby with HLHS, surprised that the girl was even still alive, spoke with the mother about the unexpected early return of Dr. Leonard Bailey who also had experience at the Hospital for Sick Children in Toronto, Canada. There, for seven years, he was involved in studies related to the treatment of infants with HLHS and a large number of experimental surgeries. Dr. Bailey informed a press conference held that same month, "...what those babies needed, really, was heart replacement."^{iv}

At the hospital in Toronto there had been studies of heart transplantations from animal donors. Newborn goats were receiving hearts from other subspecies of goats with Cyclosporine to prevent rejection; the life expectancy of the recipients was indefinite. If the donor was either a piglet or lamb, the life expectancy, with treatment by Cyclosporine and Azathioprine, was a little over thirty days and one hundred sixty-five days, respectively. With human xenograft transplantation the picture was a bit grim.

"We were a little stymied about how we were going to find donors for human babies. No one was volunteering dead babies' hearts for transplantation, and so we began to actually study the possibility of cross-species transplantation using baby baboons. We had a number, a litany really, of babies that came and were diagnosed and died. And for whatever reasons along came this baby, Stephanie Fae."^v

Dr. Bailey asked to speak directly with Ms. Beauclair in a conference at the medical center – a communication commonly called "informed consent"; so she traveled back to Loma Linda and discussed the experimental surgery with Dr. Bailey for more than seven hours. Ms. Beauclair said, "We went over all of the seven years of research that he had done."^{vi} An alternative procedure to transplantation that was relatively new at

the time had been developed by Dr. William Norwood in Philadelphia. This method, with variations to accommodate the individual patient's need, is to reroute the systemic de-oxygenated blood directly to the lungs and have the right side of the heart perform the work that the left side is originally designed to do, pump the oxygenated blood throughout the body. At that time, the success rate for the first stage of Dr. Norwood's procedure was forty percent; the oldest living child was four-years-old. Four of those children had undergone the second stage by this time and two of those children survived.^{vii} No child had yet been given the third, and final, stage of the Norwood procedure. Dr. Gregory Pence, of the School of Medicine and Department of Philosophy at the University of Alabama at Birmingham, commented on the case:

“A third ethical issue concerned informed consent. Did Bailey carefully describe the alternative Norwood procedure, with a 40 percent success rate...to Fae's parents? Or that it might be used until a human heart was found? ...An old saying always evokes knowing smiles among physicians: 'Beware the surgeon with one case.' William DeVries suffered criticisms that he only demonstrated the 'clinical feasibility' of the artificial heart, not its 'clinical usefulness.' Did Baby Fae's parents understand that their child's operation might merely demonstrate the former?”^{viii}

Ms. Beauclair said that Dr. Bailey had informed her about the Norwood procedure that day; but, would not perform the operation on her daughter because he had not had reasonable confidence that he would be very successful with it. He directed her to the Philadelphia hospital if that was the option she felt she would take.^{ix}

Xenografting was not completely unheard of in 1984. The first recorded cross-species transplantation occurred in 1682 when part of a dog's bone was used in a Russian aristocrat's injured skull. In 1963 and 1964, there were kidney transplantations from chimpanzees and baboons to adult humans in Denver and New Orleans. Most of these patients died within three weeks. One patient in Denver survived a little over three

months; one other, in New Orleans, lived for nine months. In 1964 a chimpanzee heart was transplanted by Dr. James D. Hardy in Jackson, Mississippi. This patient lived less than two hours.^x There is also a reference to a British cardiologist named Yocoub who connected the veins and arteries of a one-year-old dying boy to those of a living baboon in 1975. Until Baby Fae, he was the youngest xenograft patient on record; neither the boy nor the baboon survived the operation.^{xi}

After the long talk with Dr. Bailey, Ms. Beauclair gave the surgeon the written authorization to perform the testing on her daughter to determine which of the twelve baboons that the medical center had in the facility would be the best match. Loma Linda's Institutional Review Board (IRB) had investigated Dr. Bailey's plan over fourteen months and offered its approval in December of 1983.^{xii} Dr. Bailey described this process as "months of agonizing". Final approval was granted by them two days prior to the surgery.^{xiii}

Dr. Pence stated that, "Loma Linda refused to make public the informed consent documents signed by the parents of Baby Fae. There are also newspaper reports of Baby Fae's mother idolizing Dr. Bailey."^{xiv} But, these statements do not agree with her own testimony, "I wondered if the Dr. was a mad scientist. I'm sure I had the same reaction that anybody else who first heard it (would have)."^{xv} Dr. Bailey reflected back on that conference, "And so we went over everything and tried to be pretty objective about it – that it was highly experimental, we weren't sure where it was headed; but, without it the baby was going to die."^{xvi}

Dr. Sandra Nehlsen-Cannarella, an external immunologist and consultant to Loma Linda, was in charge of determining which baboon was the most suitable match. Baby

Fae showed the least reaction immunologically to the baboon that was selected, a nine-month-old female named Goobers. The surgery date was set for October 26, 1984.

The nursing staff of Unit 7100, Cardio-Thoracic Surgery, where Baby Fae was being treated was supportive of the procedure. Regarding her nurses, Marie Whisman Hodgkins, the unit manager, said, “They had worked with babies with severe heart defects, they had worked with babies that had gone through attempted surgical repairs for the left-hypo-plastic, (and) they *all* had worked with Dr. Bailey. *Again*, the rationale and the intentions behind this surgery were not even a question for them; we were going to help the baby.”^{xvii}

The timing of the operation seemed to come naturally. The day prior to the surgery, the infant almost died as her lungs began to fill with fluid from the heart failure. It was essential to move quickly. Dr. Nehlsen-Cannarella spoke about the final moments before the surgery,

“At six o’clock the three of us met: Len Bailey, Waldo Concepcion, and myself...and made our final plans and Waldo and I decided to go for a walk...we were walking away from the hospital and we were watching the time because we knew we had to be back at six-thirty to start, and when we turned around the clouds opened up and the sun came out and a rainbow came right down into the institution. It was just a phenomenon that just, I will never forget. And I said, ‘You know, Waldo, this is going to happen and it’s going to be okay.’ Because you can imagine how nervous we were, we were scared to death.”^{xviii}

News of the procedure was kept confidential because of the anticipated firestorm of reaction by the public, the media, and animal rights advocates. Ms. Beauclair requested that press release be delayed until after the surgery; she also asked that all identities be kept out of the story. Her one concession to Loma Linda about the story was to allow the use of Stephanie’s middle name to identify the recipient. From that time, the world only knew the infant as Baby Fae. The hospital staff was instructed about the

importance of absolute confidentiality and the strictest security measures were activated to protect the identity of both mother and baby.

Dr. Nehlsen-Cannarella, talking about the surgery stated,

“Then we started down the journey of one of the hardest things we had to do, and that was to take that animal. Because we felt very close to these animals (weeping)...Sorry...it still bothers me. It’s very difficult to makes these decisions sometimes.”^{xix}

The donor heart beat spontaneously as Stephanie’s body rewarmed from sixty-eight to ninety-eight degrees. From the time that she was taken to the surgery suite until she returned to Unit 7100 for recovery was nearly ten hours.

For many, the biggest ethical concern is that a baboon cannot be informed about the procedure, nor can it give consent. “Antivivisectionists around the country and abroad protested what they called ‘ghoulish tinkering’ with human and animal life. ‘This is medical sensationalism at the expense of Baby Fae, her family and the baboon,’ charged Lucy Shelton of People for the Ethical Treatment of Animals.”^{xx} Once the news broke regarding the surgery, protesters gathered outside the hospital carrying signs that read: Animal Research is Scientific Fraud, Animal Experiments Never Cured Anything, Animal Researchers Are Quacks, and the like.^{xxi} Philosopher Tom Regan wrote in February of 1985 that the baboon was more than a resource for Baby Fae’s body, “Those people who seized [Goobers’] heart, even if they were motivated by their concern for Baby Fae, grievously violated Goobers’ right to be treated with respect.”^{xxii} Another media piece covered the story with this part of an interview of “Michael Giannelli, science adviser for the Fund for Animals..., ‘I don’t believe what was done was in the best interest of Baby Fae,’ he said, adding caustically, ‘It may have been in the best interest of Loma Linda doctors.’”^{xxiii} Dr. Bailey rebuffed the animal rights protagonists’ argument,

“Their ‘sensitivity,’ he contends, ‘is born of a luxurious society... When it gets down to a human living or dying, there shouldn’t be any question.’ (Am. Med News, 11/16/84, p. 18).”^{xxiv} A reporter for U.S. News and World Report interviewed Dr. Jack Provonsha, the director of Loma Linda University’s Center for Christian Bioethics on November 5, 1984. The Dr. was asked about the possibility that the baboon is “sacrificed for a chancy operation.”^{xxv} His answer:

“We do not know what the possibilities are for success or even what constitutes full success. A crystal ball is not an item in our medical equipment. Rejection, of course, means trouble. All we can say is that the baby would have a chance with the surgery.”

“On an ethical-value scale, we will always place human beings ahead of sub-humans, especially in a situation where people can be genuinely served by animals. That is the story of mankind from the very beginning. Animals, for example, have always been used for food and clothing.”

“I would not want to sacrifice even a baboon meaninglessly, however. But to do so to save the life of a baby seems to me to be perfectly in order.”^{xxvi}

Baby Fae was placed on Cyclosporine-A to prevent her own body from rejecting the baboon’s heart. Her own immunities were just beginning to discern “self” from “non-self”; but, the baboon at three-months-old had a clear demarcation of what was “self.” All went well for the first couple of weeks. It took only a matter of days before the baby became the new world-record-holder for survival after a cardiac xenograft. The doctors held few press conferences and instead stayed primarily with their patient in intensive care. “Nine days after the operation, with Baby Fae seemingly doing fine, Bailey enthusiastically predicted that Fae might celebrate her 20th birthday. He predicted that Goober’s heart would grow as Fae grew.”^{xxvii} On November 4th she was offered full-strength formula for the first time since the operation. The next day they reported that she was “eating normally, grasping at objects and wailing with a ‘lusty cry.’”^{xxviii}



On November 8th pictures were released showing Baby Fae listening to her mother's voice on the phone. Due to being ill, Ms. Beauclair was not able to visit with her daughter. The hospital made available the room next to Baby Fae and the mother, from there, was able to watch her daughter's progress. Ms. Beauclair said of a picture that became famous during the time of Stephanie's post-operative recovery period, "I think I might have been reading her a nursery rhyme. I would just talk to her and...it always looked like she was trying to, you know, look around because she heard my voice. I always thought she was trying to find me...I never got to hold her after surgery."^{xxix}

On November 11th the baby started to decline; but responded favorably to treatment. The next day, as her condition continued to worsen, she was returned to the ventilator and intravenous nutrition so that her system would have less stress upon it. The doctors were trying to conserve energy for the body to fight what they at first believed to be rejection of the donor heart. Dr. Nehlsen-Cannarella stated that, because Stephanie's organs were shutting down, not the donor heart, it resembled a Graft-Versus-Host (GVH) assault on the body of the recipient. Another possible cause was the immunosuppressant, Cyclosporine-A. Two things are known about it: 1) it had only been recently approved by the FDA, so therapeutic level for an infant was unknown and, 2) a side-effect is

nephrotoxicity. The child's health continued to worsen until, at nine p.m. on the 15th of that month, she lost her struggle for survival. At ten a.m. on the 16th Dr. Bailey held another press conference and stated, "Today we grieve the loss of this precious life...which could have been an absolute loss to her loved ones...her unique place in our memories will derive from what she and her parents have done to give rise to a ray of hope for the babies to come."^{xxx} Twenty-five years after Baby Fae took her place in history he added, "To this day we don't know for sure what all conspired to take her life. But, I am comforted in the fact that we made an effort to save her life. Her family are comforted with the notion that they did all they could do to save Baby Fae, to grow up in this world."^{xxxi} Ms. Beauclair told an interviewer, "The night that Stephanie died I asked Dr. Bailey to not let this experience be wasted, and to keep going forward with it; and he did."^{xxxii} This was the only recorded attempt at such an experimental procedure. Dr. Bailey did, however, stay with the transplant protocol rather than the Norton procedure. Within one year Loma Linda was able to locate a human donor and the xenograft transplant protocol was abandoned.

"More than any other industry, it is in the healthcare business that ethics are of utmost importance. This is because, people in this industry deal with such situations and circumstances, everyday, which have a direct bearing on another person's life."^{xxxiii}

Medical professionals are presented with numerous ethical questions that need answering on an almost daily basis. As is evident in the story of Baby Fae, some of these can be more difficult to contend with than others; but, they all affect the person who is exposed to them in one manner or another. In each of us there is an indefatigable desire to

second guess decisions that others have made, whether they affect us or not. In the case of Baby Fae there is the core ethical question regarding the taking of an innocent animal's life to attempt to save the life of an innocent human.

Dr. Pence gave the reader one issue: informed consent. At the time of the writing of his book, 1990, Loma Linda University Medical Center had not released to the public the paperwork that revealed what was and was not covered in Dr. Bailey's meeting with Ms. Beauclair. Many just wish to know if the Norton procedure was discussed as an option over xenotransplantation. According to Dr. Pence, whether that surgery was discussed or not would not have swayed Dr. Bailey's determination to transplant Baby Fae's heart because "Bailey claims that children did not do well enough after the Norwood procedure to justify performing the operation."^{xxxiv}

Another ethical question is this: was there an attempt to find a human transplant donor? On October 29th, 1984, Dr. Bailey revealed that he had not done so. His reason was, "the availability of size-matched human donors is such (that) it makes that avenue impractical with our current abilities of organ procurement."^{xxxv} An early report that a two-month old baby's heart was located on the day Baby Fae went into surgery irked some vivisection antagonists. The availability of the heart before the completion of Baby Fae's transplant was later proven to be untrue.^{xxxvi}

In addition, there is the question of the breadth of the release of information regarding the procedure and the parents of the infant. The press was a challenge to the doctors and the family alike. Dr. Nehlsen-Cannarella stated, "Oh my goodness! The media, you know...I have respect for the fact that we have...the First Amendment and we need to know what's going on in the news and all...these people have to earn their

living; we may not always agree with how they do it,; but it's a reality of life"^{xxxvii} Dr. Arthur Caplan, a bioethicist from the University of Pennsylvania, put the reporters behavior into context. The media's interest was elevated because it was relatively recent history since the artificial heart transplant of Barney Clark and the ethical questions that had presented. His comments include, "I would go so far as to say if the artificial heart experiment had not been so close in time to the Baby Fae procedure I'm not sure it would have gotten quite the national attention. It's almost like you've primed the pump for more discussion of Baby Fae."^{xxxviii} Ms. Beauclair added, "There were so many reporters, and picketers, and so many things that were distractive...I was young and I was scared and I wanted everybody to leave me alone, and it just wasn't happening."^{xxxix}

"NBC has learned the identity of the child's parents. We will respect their wishes and not name them. However, certain aspects of their past might be relevant to some of the medical controversies in this case. According to relatives and court records, the couple were never married. They had separated by the time the infant was born. Both had been in trouble with the law in the state they came from, the father for disorderly conduct, the mother for passing bad checks. They had little money when the child was born."^{xl}

Did any of this revelation have anything to do with the case of Baby Fae? No. Does it have anything to do with ethics? Yes. Each of the staff members of Loma Linda went home to read, watch, or listen to reportage – true or false – regarding the mother of an infant in their care. With that information implanted in the minds of the hospital employees, care for the patient can become occluded with biases that need not be there.

"Suffice to say that we err whenever we confuse what really happens with what we would say about what happens, or what should happen."^{xli}

In order for a person to make a decision based on an ethic, one needs to understand that a foundation on which that decision is made must first be in place.

Individuals, families and cultures all differ as do the values which they hold sacred.

As a philosophy, it goes without saying that ethics are debatable. One dictionary defines philosophy, in part, as a search for a *general* understanding of values and reality by chiefly *speculative* rather than observational means (italics added).^{xiii} Therefore, the concept of an ethic is not easy to lock into a set of parameters.

Ethical decision making within the medical field, or nearly any other area, has numerous components that many practitioners may disagree upon in detail; but, agree upon in general. Karen Strohm Kitchener, while on faculty at the University of Denver, listed the following principles that seem to be held in esteem by a large number of ethicists:

- 1) The principle of autonomy allows for independence in making a decision. Much like the parent of a teen places the good and the bad of a decision before the adolescent, a wise counselor will place before his client a number of things to consider before pulling back and allowing that person the ability to decide on his or her own and enjoy the benefits or suffer the consequences of that decision. Of course, one corollary to this concept is the ability of the person making the decision to competently decide – hopefully after careful consideration of both sides of the issue. Some people, namely children and mentally challenged persons, could not conscientiously be afforded the ability to choose harm for self or others.
 - 2) The principle of non-maleficence requires that one “do no harm to others.” The theory of all these concepts regarding the foundation of ethical decision making is that they are all of equal importance; in practicality this one outweighs the others.
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- 3) The next principle is that of beneficence, the act of doing good for others. To be beneficent is not only to help another in his or her time of need; but, also to be proactive in that habit.
- 4) Kitchener described the next principle as “treating equals equally and un-equals unequally but in proportion to their relevant differences.”^{xliii} This is the principle of justice. Notice that the concept is not to treat *everyone* equally. The principled exerciser of this concept *must*, if treating certain people unequally, have rationale for why these people are being treated in that manner.
- 5) The principle of fidelity, “involves the notions of loyalty, faithfulness, and honoring commitments.”^{xliv} A trusting therapeutic relationship can be difficult to establish and even more of a challenge to maintain. This does not offer an excuse for failure to either party; rather it sets the standard that the relationship needs to attain.

There are numerous models used for the actual *act* of making the decision, which stands to reason given the previously mentioned reality that people are different from each other. If one wants to create an effective system to make ethical decisions, it would be best for the individual to study the decision making process of others and discern the best course of action for oneself. That is how the method described below was compiled.

- 1) Clearly define what the problem actually is. Cut the theories, opinions, and other confusing items away from the facts and look at what decision needs to be made. Put all options on the table in order to see the benefits and liabilities of each. Eliminate illegal and immoral alternatives, it may be necessary to seek legal

counsel in this aspect. Investigate those that remain for the ethical value that each contains. In the case of Baby Fae, this would be during the period of informed consent, when Dr. Bailey discussed the infant's condition with Ms. Beauclair and the various plans of treatment available.

- 2) Determine where your loyalties are and prioritize them. One source listed these: God, Law, Parents, Employer, and Codes (external).^{xlv} Often, when a person has competing loyalties, one party benefits while the other suffers loss. Take as an example the decision to work overtime or go home to the family. As a Seventh Day Adventist organization, Loma Linda University attributed its ultimate allegiance to a Supreme Deity. Ms. Beauclair, who was raised as a Catholic, also ascribed loyalty to a Creator, "I don't know why it all started with her. Only God knows."^{xlvi}
 - 3) Determine whether or not a similar case has been addressed before. Weigh out the decision for or against a code of ethics. These include: National Association of Social Workers, American Nurses Association, International Council of Nurses, and the American Medical Association. Almost every profession has at least one code of ethics that applies directly to it and can be found with an easy on-line search. If a similar case has been addressed according to the code that fits this case, the standards that the code outlines may then be applied. If there is no precedent set in the code of ethics researched, there are other options to work with. Consult other professionals or supervisors that may be able to assist in reaching the right decision. Dr. Bailey, in the incident with Baby Fae, had enough understanding of the Norwood procedure and extensive experience with
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- xenotransplantation. There is no evidence that is readily available to discern whether or not he had researched the primate-to-human ethics himself; the hospital's IRB had taken fourteen months to research and approve the procedure so it is most likely safe to assume that *it* had.
- 4) Evaluate the options in light of the standards and/or counsel at hand. Now, make the decision. This step was entirely left in the hands of Stephanie Fae's parents – what they decided not only affected the life of their daughter; but, also the life of a young baboon. Ms. Beauclair said that she had her own time of denial a few days after the consult with Dr. Bailey as she recalled “Well, maybe she's not really going to die, maybe I need to get a second opinion. I'd even made an appointment with a pediatric-cardiac surgeon to have her checked again.”^{xlvi}
 - 5) Once the decision has been made, plan its implementation. Seek out ways to maximize the benefits while minimizing the liabilities. This would be in the hands of the hospital staff. They were confident in their own abilities and in the plan of care that they would offer. Dr. Bailey's initial press conference after the surgery included, “The good news is that we have a beautiful healthy baby...we're pleased about that. And, in fact we expected that.”^{xlvi}
 - 6) Lastly, evaluate the action that was taken. See what the effect of the decision has been and revise on a continuous basis. Again, there may not be only one way to adjust the plan. Look for all options that are legal and beneficial. Dr. Bailey moved to a human-to-human protocol only after Baby Fae's death. This was ideal from the outset, even in the mind of Dr. Bailey. One of the effects of the world-wide notoriety of Baby Fae was that parents of dead or dying infants now began
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to offer those children so that others could live.

One author, Lisa Newton, has put together an acronym that can be utilized to making the ethical decision: DISORDER.

- 1) D – Definition of the Dilemma
 - 2) I – Inquiry for Information
 - 3) S – Stakeholders
 - 4) O – Options and Outcomes
 - 5) R – Rights and Rules
 - 6) D – Determination of Decision
 - 7) E – Evaluation of Effects
 - 8) R – Review and Reconsideration^{xlix}
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“There are too many occasions when someone knows what is the right or principled thing to do but fails to act on those principles because of what we might consider to be a character flaw or acts out of principle but with little compassion or kindness for the person affected by his or her actions... Others may know moral rules or principles and in most cases adhere to them, but they seem to lack an in-depth understanding of what it means to be moral and may cut ethical corners even in their response to professional requirements.”^l

No matter the profession, the path to ethical decision making is inevitable. As a nursing student and nurse’s aide, this author has already had a couple years of experience immersed in the thick of having to witness or make a decision based upon an ethic. Especially as a student, there is a shielding – of sorts – that exists as protection from being forced into making a life-altering decision. The licensed nurses and clinical instructors are there for counsel should a situation arise that could create an environment where a decision to act or not act needs to be made. There is no record of a nurse being

directly involved in the decision that either Dr. Bailey or Teresa Beauclair made; as, followers of orders, rather than makers of orders – the likelihood of that happening is slim. But, there are times when the nurse needs to know what to do as the intercessor between patient, or patient’s family, and medical/surgical staff. In that instance, does the nurse have the wherewithal at hand to assist him/her to advocate in the best interest of the patient? That is a skill that is up to the nurse to develop should the recognition of a deficiency occur. The primary goal of the nurse is non-judgmental care for the patient. In this way the nurse must perform an almost impossible task and empty his/her mind of prejudice for/against the patient. The nurses on Unit 7100 of Loma Linda University Medical Center *did* that in the midst of controversy over the loss of an animal so that a human could live, they remained silent about the child before and after the procedure for her sake and the sake of her family, and did not remark about the way some of the media was portraying Baby Fae’s parents.

Some questions for the nurse or nursing student remain. It has been more than twenty-six years since Baby Fae lived and died with a baboon heart keeping her blood flowing and her body alive. In the time that has passed, how has the profession changed to reflect the need for the evolution of ethical principles? Why was the Health Insurance Portability and Accountability Act of 1996 (HIPAA) found to be necessary? Is it still needed; is there a need for adjustment now? How can a nursing student prepare, or become better prepared, to contend with ethical dilemmas? Could ethics, or rather *should*, a course in ethics be required for nursing students? Can ethics be placed into simulation scenarios?

The goal of this work is for the nurse, or any other reader, to understand that life

is not a sequence of black-and-white decisions that need each person's discernment. The story of Baby Fae was a vehicle on which to carry this idea into the reader's mind. A day is coming when each of us will face a predicament that we would rather not be in. Some will be minor, some will not. What were presented here are the facts, simply stated, regarding an historical event that had a profound effect upon medical history. Nurses played a role in it that other nurses can emulate, working professionally in the face of great opposition, retaining patient privacy rights, and realizing that we cannot always have a vote about which side of the case we would like to be on, functioning as a patient advocate non-judgmentally. As stated in the opening paragraph, it can be easy to laud or criticize an historical event; but, we do not live in history – we only hope to learn from it.

End Notes

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- i Peart, Neil; Lee, Geddy; Lifeson, Alex. "Witch Hunt." *Moving Pictures*. Mercury Records, 1981. CD.
- ii Ibid.
- iii Beauclair, Teresa. Personal interview. 6 January, 2011.
- iv "Stephanie's Heart: The Story of Baby Fae."
- v Ibid.
- vi Beauclair, Teresa. Personal Interview 6 January, 2011.
- vii Chu, Dan and Hoover, Eleanor. "Helped by a Baboon Heart, An Imperiled Infant, 'Baby Fae,' Beat the Medical Odds." *People Weekly*. Time, Inc., 19 November 1984. Web. 30 March 2011.
- viii Pence, Gregory E., Ph.D. *Classic Cases in Medical Ethics: Accounts of the cases That Have Shaped Medical Ethics, with Philosophical, Legal, and Historical Backgrounds*. New York: McGraw-Hill, 1990. Print. (254,5)
- ix Beauclair, Teresa. Personal Interview 8 April, 2011.
- x "The History of Xenotransplantation." BBC News. Sci/Tech. 19 August 1999. Web. 29 March 2011.
- xi Pence, Gregory E. (251)
- xii Ibid. (255)
- xiii Wallace, Claudia. "Baby Fae Stuns the World." *Time*. Time, Inc., 12 November 1984. Web. 23 January 2011.
- xiv Ibid.
- xv "Stephanie's Heart: The Story of Baby Fae."
- xvi Ibid.
- xvii Ibid.
- xviii Ibid.
- xix Ibid.
- xx Wallace, Claudia.
- xxi "Stephanie's Heart: The Story of Baby Fae."
- xxii Pence, Gregory E. (253)
- xxiii Chu, Dan and Hoover, Eleanor.
- xxiv Mistichelli, Judith Adams. "Baby Fae: Ethical Issues Surrounding Cross-Species Organ Transplantation." *National Reference Center for Bioethics Literature*. The Joseph and Rose Kennedy Institute of Ethics, Georgetown University, January 1985. Web. 31 March 2011.
- xxv "Use Animal Organs for Human Transplants?" *U.S. News and World Report*. Pro and Con, pg. 58, 12 November 1984. LexisNexis Academic. Web. 31 March 2011.
- xxvi Ibid.
- xxvii Pence, Gregory E. (253)
- xxviii Chronology of Baby Fae. *Scope, January-March, 1985*. Loma Linda University Medical Center. Web. 30 March 2011.
- xxix "Stephanie's Heart: The Story of Baby Fae."
- xxx Ibid.
- xxxi Ibid.
- xxxii Ibid.
- xxxiii Dogra, Aastha. "Ethical Issues in Healthcare." *Buzzle.com, Intelligent Life on the Web*. 3 March 2010. Web. 6 April 2011.
- xxxiv Pence, Gregory E. (258)
- xxxv Altman, Lawrence K. "Baby With Baboon Heart Better; Surgeons Defend the Experiment" *The New York Times*. 30 October 1984. Web. 16 January 2011.
- xxxvi Chu, Dan and Hoover, Eleanor.
- xxxvii "Stephanie's Heart: The Story of Baby Fae."
- xxxviii Ibid.
- xxxix Ibid.
- xl Ibid.
- xli Herrera, C.D. "How are Ethics and Law Related?" *Bioethics Discussion Pages*. 2000. Web. 2 February, 2011.
- xlii "philosophy" *Merriam-Webster Dictionary*. Web, 4 March 2010.
- xliiii Kitchener, K.S. *Intuition, critical evaluation and ethical principles: The foundation for ethical decisions in counseling psychology*. *Counseling Psychologist*, 12(3), page 49, 1984.
- xliv Davis, Thomas; Forester-Miller, Holly. A Practitioner's Guide to Ethical Decision Making. Web, 28 Feb 2011.
- xlv Ethical Decision-making Models Across the Professions, March 20, 2003. *Ethical Reflections and Reasoning Rule/Code Obedience/Conventions, Gut Reaction*. Web. 28 Feb 2011
- xlvi "Stephanie's Heart: The Story of Baby Fae."
- xlv Ibid.
- xlvii Beauclair, Teresa. Personal Interview 6 January, 2011.
- xlviii "Stephanie's Heart: The Story of Baby Fae."
- xlix Ethical Decision-making Models Across the Professions
- 1 Kitchener, Karen Strohm. "There is More to Ethics Than Principles." *The Counseling Psychologist, Volume 24, Number 1*. January 1996. Web. 3 March 2011.
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