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## Preservation of Autonomy in Pediatric Decision-Making

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# Preservation of Autonomy in Pediatric Decision-Making

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A Thesis Submitted to The Graduate School at the University of Missouri-St. Louis  
in partial fulfillment of the requirements for the degree  
Master of Arts in Philosophy

May 2022

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## **Abstract**

Pediatric patients must rely on proxy decision-makers to make their health care choices for them. There are three main frameworks in place for such decision-making: the best interest standard, the harm principle, and the child rights approach. The default is usually that the decision-maker will make the decision that they feel is in the best interest of the child. Limitations on the decision-maker are an aspect often discussed with abuse and neglect at the forefront as thresholds for when limitations and intervention are deemed necessary. Concern for the child's future autonomy is not typically considered. Instead, the values and beliefs of the decision-maker are used to validate the choices made for the child. I argue that it should be the responsibility of those involved in the decision-making process to preserve the future autonomy of the child. This leads to the question of whether a decision should be made now or held in reserve for the future, if possible. In situations where postponement is not possible, such as a life-threatening or serious health condition, the assurance of a future where the child has the ability to become autonomous should then be the first consideration.

## **I. Introduction**

Pediatric patients require specialized care that considers their developing minds and bodies. Those who diagnose and treat pediatric patients must consider their age, size, and development. Because the cognitive capacities of pediatric patients are not fully developed, others make medical decisions for them. The decision-maker is usually a parent or legal guardian, who must consider what is good for the patient. But it is my view that decision-makers have an additional responsibility: they must preserve the patient's future autonomy. This fact, I argue, limits what proxy decision-makers may do. They should choose medical treatment for a child only when it is necessary for the patient's physical health or provides an immediate improvement in quality of life. All other medical treatments, such as those that do not improve physical health, or those based only on the moral and religious views of the proxy decision-maker, should be delayed until the child is old enough to exercise their autonomy. This excludes immediate issues where a future autonomous decision is not possible, as may be the case if the procedure or treatment can only be performed at a young age and is not an option for an adult.

In the first two sections of this paper, I will discuss what is generally accepted as valid concerns that should be addressed in the field of bioethics. This includes an explanation of various frameworks used to guide decisions in pediatric medicine. Next, I will discuss what is missing from the current frameworks and explain why it is important through the use of various examples. Finally, I will argue that a proxy decision-maker for a pediatric patient has a responsibility to preserve the future autonomy of the patient.

## **II. The Four Main Principles in Bioethics**

I will start by discussing generally accepted ideas in the field of bioethics. By doing this, I will create a basis to use in establishing what is ethical in a medical setting. Bioethics, though not a foreign

concept at that time, really began to grow as a field of study in the 1970s. Childress and Beauchamp became pioneers in the field with their 1979 publication *Principles of Biomedical Ethics*. Together, they developed a framework of the four main principles in bioethics: respect for autonomy, nonmaleficence, beneficence, and justice (Beauchamp & Childress, 2013).

Autonomy, of course, refers to the ability to self-govern and make independent choices free from coercion (Beauchamp & Childress, 2013). The principle of nonmaleficence is the principle directing us to do no harm. This principle is often questioned in medical ethics. For example, is letting someone die an instance of harming? The principle of beneficence, by contrast, directs us to benefit the individual patient. The same questions that are associated with nonmaleficence can be directed to beneficence as well. For example, vaccines can be beneficial to someone's health, however, is it a benefit to a person if you vaccinate them against their will? Finally, the principle of justice directs us to reverse the inequalities in health care such as access, costs, and health status (Beauchamp & Childress, 2013). These four principles are vital considerations when developing bioethical frameworks.

### **III. Existing Framework**

Now that the basic principles for bioethics have been laid out, we can look at the frameworks used by proxy decision-makers to aid them in making decisions on behalf of a pediatric patient.

Frameworks guide the decision-making process and provide a basis for limiting the decision-maker to protect the patient. These guidelines provide a code to facilitate ethical decision-making; however, they are ethical standards and not legal standards.

#### **A. Best Interest Standard (BIS)**

The default standard most commonly used is the Best Interest Standard (BIS) (Bester, 2018). The BIS brings together the health care professional and the decision-maker to discuss the options available and deliberate the pros and cons of each option to determine

which is in the best interest of the child. Critics say that this is too vague and does not limit the proxy decision-maker. This framework leaves only basic options for state intervention: abuse and neglect, special circumstances of organ donation by minors, and decisions outside the boundary of community norms (Ross & Swota, 2017).

### *B. Harm Principle*

The harm principle contends that harm should be the threshold used for intervening with parental decision-making. Douglas Diekema suggests that the best interest standard does not help with deciding when intervention is warranted. The concept of what is in the best interest of the child is too subjective, and therefore Diekema finds that the harm principle fills this capacity. He has proposed eight conditions that need to be satisfied to warrant state intervention: (Diekema, 2004)

1. By refusing to consent, are the parents placing their child at significant risk of serious harm?
2. Is the harm imminent, requiring immediate action to prevent it?
3. Is the intervention that has been refused necessary to prevent the serious harm?
4. Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?
5. Does the intervention that has been refused by the parents not also place the child significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7. Can the state intervention be generalized to all other similar situations?

8. Would most parents agree that the state intervention was reasonable?

Once these questions are satisfied, then there is adequate justification for state intervention to protect the child.

C. *Child Rights Approach*

This framework views children as independent rights holders. The United Nations Convention on the Rights of the Child occurred in 1989, outlined what they constituted to be the rights of every child. The articles of the convention are not specific to healthcare issues and include aspects of the child's overall life and well-being. In "Beyond Bioethics: A Child Rights-Based Approach to Complex Medical Decision-Making," the analysis noted three key values from the convention: (Unicef, 1989)

1. Family is important and central to a child's upbringing and overall well-being. Therefore, family responsibilities, rights, and duties should be respected.
2. Decisions regarding a child should be made based on what is in the best interest of the child.
3. Children should be involved in decisions concerning them, in so far as possible. As they mature, they should exercise increasing control over such choices and have access to more and more information. Children have several social and political rights that states and parents must respect.

To consider the child as an individual rights holder improves decision-making. Article 6 of the convention confirms a child's right to life, while Article 24 specifies that the child has a right to the best standard of health available and that the State Parties must take steps to ensure that the child is not deprived of these rights (Unicef, 1989). This agreement was signed by U.S. President Bill Clinton in 1995; however, it has never been ratified. There is some concern in the U.S. that such an outline focusing on the child's rights may limit

parental control undue.

#### **IV. What's Missing**

The frameworks mentioned in Section III are the most widely accepted in pediatric decision-making. Each framework has its good and bad points. Various arguments have been made for and against each version. Suggestions have been made for combining versions, using one to supplement another. In these arguments, we can see that there is a question of possible limitations on the decision-maker, but they are focused on preventing immediate harm. The limitations argument does not mention a need to preserve the child's future autonomy. The concept of preserving autonomy is analyzed and developed by Dena Davis when she referred to a "child's right to an open future" (Davis, 1997). The idea is that the child has certain rights that are entrusted to the decision-maker, who in turn protects those rights until the child can make use of them.

While the child rights approach does concern itself with some limitations on proxy-decision makers in favor of the individual rights of the child, it does not go far enough. The outlined rights provided by the U.N. are more concerned with the general treatment of children, not specifically with decisions made on behalf of the child in a medical setting. The treatment of children in general, as the child rights approach is concerned with, does not concern itself with the possible reduction of choices that should be made by the future autonomous individual. This is where my concern is focused, that there are decisions made that should be postponed until the child has matured and can exercise autonomy.

In the currently available frameworks, a decision-maker can break this trust. They could make a decision without attending to how it may limit the patient in the future. An example of this is found in the treatment of intersex patients. When an infant is born with ambiguous genitalia, the health care providers, in conjunction with decision-makers, assign a sex and perform surgery on the genitals of the infant so that they more closely match that of the assigned sex. This is an irreversible



procedure. Moreover, it is not necessary for the physical health of the child, may lead to future health problems, and not fit the identity the child develops as they mature. Instead, if the child decides to have the surgery in the future, it is still possible for them to choose to have the procedure. I will delve more deeply into this example in section VI when discussing irreversible procedures.

There may be those who argue that possible future health issues themselves, as mentioned in the previous paragraph, would constitute harm, and are therefore addressed by the current frameworks. However, even without concerns about possible health problems, the decision-maker should preserve the patient's autonomy. A procedure that is not required for the physical health of the patient is an unnecessary procedure. Unnecessary medical procedures are done because of the personal preferences of the decision-maker in the situation. If this is the case, the decision should be an autonomous one based on the wants or desires of the individual patient.

Consider a situation in which a 25-year-old woman is temporarily unable to assert her autonomy. She is in a medically induced coma while a head injury is healing. During this time, her parents are responsible for making her medical decisions. The doctors have stated that the coma is temporary and they expect a full recovery. While in the coma, it is discovered that she has the BRCA2 gene mutation that increases a woman's chance of developing breast cancer by the age of 70-80 years of age from 13% for the average woman to 45-69% (National Cancer Institute, 2020). In fear of possible cancer for their daughter, the parents consider authorizing a full mastectomy as a preventive measure to keep their daughter from developing breast cancer. There is a possible future risk to their daughter and they are responsible for her decision-making at this time. Do they have the responsibility to act now, or to preserve their daughter's future autonomy to make the decision herself once the induced coma has been reversed? I believe most would argue that it is up to the daughter, and since there is no immediate danger, it can wait for her future autonomous decision.

The above example has much in common with the pediatric decisions that are being

questioned in this paper. The main difference concerns the length of time until the patient's autonomy can be asserted. When a patient will become autonomous the decision should be postponed. Just as the parents of the woman in the induced coma have a responsibility not to make unnecessary decisions for their daughter, a proxy decision-maker for a child has a responsibility to make only decisions that provide immediate value to health or quality of life.

## **V. Beliefs and Values**

While making use of the available decision-making frameworks, there is still an aspect of the process that favors the decision-maker over the patient. This aspect pertains to beliefs and values, and the assumption that the decision maker's beliefs and values are always sufficient in the decision-making process. Proxy decision-makers often rely on their personal beliefs and values to make a decision. On the surface, this seems reasonable. However, again, we must consider whether there should be limits to exercising these values. While it is acceptable and even expected for health workers to do what they can to accommodate these special circumstances, it should not be at the expense of the autonomy of the child.

The child's rights approach mentioned earlier establishes the right to life and the best healthcare available is established. Though, culture, family, and religion remain important. Article 14 discusses a child's right to religion, and Article 30 states that those belonging to a religious minority have a right to profess and practice their religion (Unicef, 1989). However, I question whether this stands in life-or-death situations.

Consider the beliefs of the Jehovah's Witness community. Jehovah's Witnesses consider blood transfusion to be a risk to their salvation and will usually refuse the procedure. If there are alternatives to blood transfusion that accommodate the decision-maker's religious beliefs without risking the child's health, then, of course, it is reasonable to provide such an alternative. If, on the other hand, blood transfusion is the only medically beneficial option, it should not be denied based

on the religious values of the decision-maker. The decision-maker may have the autonomy to refuse the procedure for themselves, but not for the child in question. If the child is deemed not mature enough to make their own medical decisions, then they are not mature enough to claim a deep-seated belief in a particular religion.

A family's beliefs and values can also play a positive and significant role in medical decision-making. Medical breakthroughs and innovation can be impacted by personal beliefs and values in a positive way. Consider a parent of a child with pediatric epilepsy who does not respond well to typical medications used to treat the condition. A parent with an interest in alternative medicines may begin to research options not offered by western medicine. Drug Science reported a case study of parents who decided to explore the use of medical cannabis in the treatment of their son's epilepsy (Johnson, 2021). The parents tracked their son's seizure activity and reported a 60-80% reduction in the frequency through the use of medical cannabis, in addition to a reduction in the severity of the seizures themselves (Johnson, 2021). The medical use of cannabis has been a controversial topic over the last decade or more. Through the determination of people with beliefs and values, such as the parents mentioned in the Drug Science case study, the acceptance of this once illegal option has grown and is now an option for those in need. By accepting the use of medical cannabis, they are not only improving the quality of life for their child but increasing the possibility for others to follow in their footsteps.

It is important to note here that it is not the purpose of this paper to limit any religious practices in a private or religious setting. Rather, the intent is to focus on decisions made and procedures performed in a medical setting.

## **VI. Irreversibility in Medical Procedures**

Making decisions based on the beliefs and values of the proxy decision-maker could have problematic consequences in cases where the procedure is irreversible. The consequences of any

medical procedure should be considered with any medical procedure, but more so in cases involving pediatric patients. Though the intention of the procedure may be to benefit the child, the actual outcome cannot be known until the child sufficiently matures to where they can choose autonomously.

This very issue arises in debates around the treatment of intersex patients. The term 'intersex' indicates a person born with traits (gonads, chromosomes, sex anatomy) that do not fit with the typical definitions of male and female. The ethics of medically treating intersex patients is addressed in *The Plasticity of Sex* (Legato et al., 2020). While varying conditions fall under the umbrella term 'intersex,' one specific example is that of an infant born with partial androgen insensitivity syndrome (PAIS). In such a case, the partial sensitivity to androgens prenatally could result in ambiguous genitalia at birth. In cases like this, it is common for physicians to assign a sex and then suggest surgical alteration of the genitalia to more closely match the assigned sex. In the case of an assignment of female, feminizing surgeries are recommended, which are described in Chapter 14 of *The Plasticity of Sex*. "Although these traits do not pose any immediate risk to life or body function, doctors often suggest feminizing genitoplasty (FG) to reduce the size of the clitoris and reshape the vulva, or vaginoplasty to create or lengthen a vagina" (Legato et al., 2020). Feminizing surgeries have been found to result in various problems in the future, such as loss of sexual sensation, painful intercourse, and incontinence. These are just a few examples of medical issues that can develop, although there is also the issue of gender identity, which may not match that of the sex assigned to them at birth.

Those who support early surgical alterations to the genitalia of these children claim that these issues improve over time as surgical techniques improve and that allowing a child to grow up with ambiguous genitalia is likely to stigmatize the child and inflict psychosocial harm (Legato et al., 2020). While some surgeons report general satisfaction among their patients who have received

such a procedure, other studies report significant dissatisfaction (Legato et al., 2020). There have been no comprehensive studies performed to determine satisfaction or dissatisfaction, which leaves the question of satisfaction inconclusive. Since there are no immediate medical benefits to the child, it becomes apparent that intersex children receive these surgeries, not for a medical need but to offset potential psychosocial harm without sufficient evidence of its existence. Refusing these surgeries, or postponing the decision, has not been found to have any negative health benefits. Instead, the child can develop naturally, at least until puberty when there may or may not be a need to discuss hormone levels for continued development. However, the need for surgical alterations is still unnecessary.

As well-meaning as these decision-makers may be, such decisions, unless medically necessary, should be reserved for the future when the child can have input into the discussion. In the case of the infant with ambiguous genitalia, there are two options available, either you can perform the surgery or not perform the surgery. If the surgery is performed, it is possible that all will be fine and the patient will be happy or there could be complications including the unhappiness of the patient. If you do not perform the surgery, it is possible that the patient is happy with themselves as they are or they are unhappy with the look of their genitalia. In scenario one, the procedure is irreversible and so the unhappy patient is stuck with the results. In scenario two, the patient may choose to have a procedure that they feel will make them happy. Scenario two is the only one where an unhappy patient can choose to alter whatever is causing their dissatisfaction.

The potential harms of this irreversible procedure outweigh the potential benefit. The child's future autonomy should be preserved. As mentioned at the end of Section IV, any procedure performed in order to satisfy a personal preference should be at the preference of the patient themselves. In the event that the patient is not competent enough to make the decision, because they have not matured enough to decide autonomously, should be postponed for discussion until a

time when the decision can be autonomous.

## **VII. Competence and Maturity**

We should next discuss a child's developing competencies. The decision-making ability of a 6-year-old is different from that of a 14-year-old. Current laws surrounding the age of consent are inconsistent and vary by state. Although for most states, the full age to have autonomy over medical decisions is 18; however many states provide conditional provisions (State Laws, 2021). For example, in many states, minors can forego parental consent for treatment pertaining to pregnancy or STDs. A pregnant minor may consent to not just medical treatment for their pregnancy but that of their child as well (Laws.com, 2020).

This is not to say that autonomy should just be given to children. Rather, we should recognize that as the child grows, their competency also grows. Children mature at different rates, and therefore an arbitrary age of consent does not necessarily represent the competency of the individual. As children reach adolescence, they should be included in the conversations over medical decisions and be allowed to express their opinions on the choices available. Those opinions should be respected on simple issues and guided on more complex issues. While the information given should be age-appropriate in order for them to grasp a true understanding.

Supporting a child exploring their autonomy is not synonymous with giving them complete control. A child will have full autonomy once they reach the age of consent and will be expected to deal with decision-making on their own, though I concede that in some cases, there is family support still in place. The transition from no control to total control can be overwhelming and confusing. This can be avoided by years of gradual inclusion in decision-making and having opinions heard and respected.

## **VIII. Concerns Over a Focus on Autonomy**

Some feel that a parent should have total control, as they will do what they deem is best for their

children. This is an understandable position as it has historically been the accepted practice in health care ethics. Now, however, we are seeing a shift toward including adolescents as we question what rights a child should have. Richard Boldt points out the need for inclusion in cases of mental health and addiction treatments, as treatments without the patient's cooperation are unlikely to be successful (Boldt, 2012). The inclusion of pediatric patients in the decision-making process can be described as a gradual process, owing to the different brain development rates and the growing ability of the child to assert themselves (Sabatello et al., 2018). In addition, some suggest that the level of inclusion may fluctuate, while the adolescent may not desire complete autonomy but instead merely be involved; the child may trust their parents to guide them to the correct decision (Sabatello et al., 2018). This is not an attempt to take control away from the parents. Instead, it is an evaluation of possible limitations to that control. For example, it would be untenable to allow a parent to decide to have their child sterilized so that they cannot have children of their own in the future. For a parent to make a drastic decision on their child's future fertility is extreme, and some may say that it is a ridiculous example. Why is that? A reasonable person may answer this question in the following way; it would be a procedure that is medically unnecessary, is irreversible, and therefore has a significant effect on the child's future life choices. This is not only because of the physical changes that would be performed but because of the impact on their overall life. The child loses the ability to experience a life of their own choosing. In other words, by not allowing child sterilization, we preserve the child's future autonomy. The question is, outside of this extreme example, are there other choices that need not and should not be made to preserve autonomy?

Consider the earlier example, in section VI, of the intersex infant born with ambiguous genitalia. A decision is being made as to the gender of the child, and surgery is used to match the genitalia to the chosen gender in order to spare the child from possible (not proven) psychosocial harm. This decision has a significant impact on the child's future choices, is irreversible, and is not

medically necessary. These are the same issues raised by child sterilization.

Some fear young people will make decisions they later regret. This is a valid concern, and I will address it. There are many reasons that a regretful decision may be made, including misunderstanding, peer pressure, or simply a change of mind. This is all the more reason to include an adolescent in the decision-making process so that they can benefit from the discussion of options as they learn to be autonomous. As discussed earlier, there is a difference between inclusion and complete control.

Often, when discussing transgender issues, there is concern that the adolescent may change their mind. Should an adolescent have the option to proceed down the path of transitioning to another gender? The answers are yes and no, but I will explain. Being supportive and accepting of this decision allows for a good relationship with the child. They should explore the options together, and even if the parent does not completely understand the choice, they can embrace it for the sake of the child. The child is developing and learning to express autonomous decisions; which should be encouraged. The parent should allow the child to engage in the transition and treat them as they wish to be treated. Often the issue comes up as the child considers using puberty-blocking treatments, which stop the development of sex characteristics. Maura Priest explains it well when she talks about the harm that can come from not allowing these treatments, such as the development of gender dysphoria. "Yet for transgender youth approaching puberty, their bodies do not feel like their property at all. Indeed, such puberty-induced changes create a body they would rather disown than own" (Priest, 2019). Allowing them to block puberty can prevent this. The good news is that should the child change their mind, puberty-blocking treatments are reversible, at least to a point as long-term effects are still being studied. Permanent surgical alterations, thus, do not need to be performed to allow the child to develop and express themselves in the way that they feel best fits them.



## **IX. Questions Over Medical Necessity**

Some may question what is meant by 'not medically necessary,' as there are many procedures that are not medically necessary. One example is cochlear implants, meant to provide a better quality of life by allowing the restoration of hearing. It is true that this is not medically necessary, and the child will not suffer physically if they do not receive the procedure. The difference here is two-fold. First, there is a known immediate benefit to the child's life. Second, and more importantly, the procedure does not take away future choices, as it is removable if, as an adult, they do not want the cochlear implant.

A more common procedure, though controversial and often debated, is the routine circumcision of male infants. I will reiterate here: it is not the intent of this paper to interfere in private religious practice in a religious setting, rather it is to look at its practice in a medical setting. I am concerned with the regularity of the procedure performed in a medical setting for non-religious reasons. The U.S. performs a high percentage of circumcisions outside of religious tradition and is an outlier compared to other countries. A study published by the World Health Organization in 2007 displayed the unusual popularity of the procedure in the United States:

We estimate that approximately 30% of the world's males aged 15 years or older are circumcised. Of these, around two-thirds (69%) are Muslim (living mainly in Asia, the Middle East and North Africa), 0.8% are Jewish, and 13% are non-Muslim and non-Jewish men living in the United States of America (World Health Organization et al., 2007).

The popularity of circumcision began to grow in the 19<sup>th</sup> century, as claims associated with health benefits began to grow (Hodgson, 2020). The procedure was thought to be a cure to a range of illnesses. Syphilis, epilepsy, and asthma are just a few examples of conditions that used to be considered to be related to non-circumcision (Carpenter, 2020). In addition, the realization of the hygienic benefits also became known at a time when there was a focus on germs and their

connection to diseases. Now the benefits are better understood. So, are the benefits of circumcision reason enough to warrant the procedure? The below lists the studied benefits: (Tobian & Gray, 2011)

1. Risk of acquiring HIV is reduced by as much as 53%
2. Some varied reduction in risk of acquiring other STDs
3. Prevention of infant UTIs
4. Reduced risk for transmission of syphilis to a female partner.
5. Reduced risk of penile cancer

At first, the list may seem to contain excellent reasons for circumcision. However, most worries can also be avoided with proper genital hygiene and teaching safe sex practices. In addition, there are now simple treatments for most minor infections. Penile cancer itself is already very rare and accounts for less than 1% of cancers found in men.

As with all surgical procedures, there are risks. One European study reported that complications occur in as much as 1.5% of procedures, though most are minor such as swelling or bleeding, and easily treated. Major complications are extremely rare, though they do exist. Studies do not settle whether sexual sensitivity is lost with the removal of the foreskin. So, we may again question why circumcision is so popular in the U.S., and if parents should be allowed to circumcise their sons. Proponents of circumcision often compare it to vaccination. If a vaccine were available that reduced the risks listed previously, would you not take it? But, is it fair to compare vaccination to any surgical procedure? While it may be true that an available vaccination with these benefits may be widely accepted, it is an altogether different notion to accept a surgical option for so little benefit.

Given the benefits and harms of circumcision are minimal, we still need to preserve autonomy, even when there is no major harm or benefit to the health of the child. The choice to maintain or remove the foreskin is not necessary for the physical health of the child, and therefore is

a personal preference of the decision-maker.

To clarify, there may indeed be some medical procedures performed that are not medically necessary. The need is to look at the complexity of the situation and determine how it may affect the future autonomous person. A mole may be removed as a precaution against skin cancer. In this case, the mole is unlikely to be of any consequence to the future individual. An orthodontist may remove teeth to prevent overcrowding and apply braces in order to align the teeth. Again, a tooth in a crowded mouth, or the movement of the teeth into a better alignment, are instances that are unlikely to be of any concern in the future. The issue here is not that we cannot perform any unnecessary procedures, but to examine the situation closely to determine if there is any chance that you could be making a decision that will have an overall impact on the future individual.

## **X. Conclusion**

Looking back to Section II, we can use the four principles of bioethics to evaluate the examples discussed so far. By performing this evaluation, we can see the four main principles support the suggestion that these procedures be postponed until the child can make an autonomous decision.

### 1. Feminizing Genitoplasty of an Intersex Infant

- a. Autonomy – Not a possibility for an infant.
- b. Nonmaleficence – While the decision-maker may believe they are not causing harm, this cannot be confirmed until the child reaches maturity. Furthermore, the risks associated with the procedure could be considered harmful. Therefore, this principle cannot justify surgery.
- c. Beneficence – While the decision-maker may believe they are benefiting the child, this cannot be confirmed until the child reaches maturity. Perceived benefits, based on assumptions and not adequate empirical evidence, cannot be used to claim this principle.

- d. Justice – This procedure is used to normalize a condition that does not fit into accepted social groups. In this example, justice would seem to be a reason not to perform the procedure.

## 2. Circumcision of Male Infants

- a. Autonomy – Not a possibility for an infant.
- b. Nonmaleficence - There are some confirmed health benefits, however, the same benefits can be achieved through proper hygiene and safe sex practices when the child reaches maturity. To use this principle to justify infant circumcision, the benefits must outweigh the risks of an elective surgical procedure.
- c. Beneficence – Since the confirmed benefits can be achieved without the surgical option, one may be less inclined to accept a claim of this principle to justify the procedure.
- d. Justice – There is no direct connection to this principle in this example, though, the lack of autonomy in an irreversible surgical alteration could be a reason to use this principle to refuse the procedure.

The above list shows how these examples are not easily justified using the ethical principles that have been widely accepted in the field of bioethics. Given this inability to justify the procedures, we may conclude that discussions and decisions concerning these procedures should be postponed until the child reaches a level of maturity and competence that would enable the future autonomous individual to make the decision themselves.

The reliance of pediatric patients on proxy decision-makers endows those decision-makers with a special responsibility to the patient. This responsibility goes beyond simple decision-making. The decision-maker is also entrusted with the preservation of the child's future autonomy. It is not enough to be concerned only with potential harms or benefits, but also to concern themselves with

the impact on the future autonomous individual. Unnecessary medical procedures are based on the personal preferences of the decision-maker and should be postponed until the individual patient can decide for themselves.

There may be treatments or procedures that, while not being completely necessary from a medical perspective, immediately improve the patient's life. Consider treatments intended to aid patients with certain disabilities or injuries, such as speech therapy or physical therapy. However, in analyzing the available decision-making frameworks, we can see that they fall short of outlining the preservation of autonomy as a responsibility.

The current frameworks are primarily concerned with making decisions that are in the best interest of the child and preventing harm to the child, but they do not take into account the future autonomous individual. While they acknowledge the need to limit proxy decision-makers, they focus on preventing immediate harm to the child. However, I argue that in addition to asking 'what is the best decision', we must also ask, 'should I be making this decision at all.' Furthermore, we must also ask, 'do I have the right to sacrifice something of the child's based on personal moral and religious views.'

The main objection from the proxy decision-makers when discussing any child rights or their responsibilities to the children in their care often stems from a concern over what is perceived as a loss of parental rights. However, this is not truly an additional loss of parental rights, at least not in the way concerns are usually discussed. Limitations on proxy decision-makers already exist in cases of abuse and neglect which are already widely accepted reasons for state intervention. This additional concern of preserving future autonomy is another aspect of these limitations that prevent abuse, in the form of abuse of power. When decision-makers make decisions that are not medically necessary and may impact the future autonomous choices available to the child, they are abusing the power they have been given by imposing their own beliefs and choices on the future

autonomous individual. Concerns for the child are not limited to issues of immediate harm; they also include the overall impact on the life of the individual. Children have a right to a future of their choosing, and decisions that limit that future, without justification, disrespect children.

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