

CHAPTER 13

ETHICS OF PAEDIATRIC SURGERY IN AFRICA

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Introduction

A paediatric surgeon not only has the responsibility to care for the young and developing patient but equally has the duty to counsel and care for the concerned parents—and sometimes their broader family members, who all live within a very specific cultural milieu with its value systems and demands. Besides surgical skills, therefore, a paediatric surgeon needs to be aware of the psychological, cultural, and ethical issues involved with the care of patients and their families. At times, this can be quite challenging.

Paediatric surgery has a long and interesting history of profound concern with providing quality of care and the many potential ethical dilemmas encountered. Old traditions as well as new technological developments can present with a quagmire of ethical dilemmas, and modern paediatric surgeons should be aware of these issues and have the cognitive and emotional maturity as well as the skills to carry out their duties in the most professional manner.

This chapter can only be a very short introduction to some important ethical issues, concentrating on the often neglected African aspects.

History

Historically, the Hippocratic Oath defined the ethical principles guiding medicine, instructing physicians to use their knowledge and skills for the benefit and protection of their patients. Over the years, a collaborative process has evolved, incorporating ethical principles of patient autonomy, respect for persons, nonmaleficence, beneficence, and justice.¹ In this model, the physician contributes medical knowledge, skill, and judgment; the patient or patient advocate personally evaluates the potential benefits and risks inherent in the proposed treatment.

Western medical ethics may be traced to guidelines on the duty of physicians in antiquity, such as the Hippocratic Oath and early rabbinic and Christian teachings. From the medieval and early modern period, the field is indebted to such Muslim physicians as Ishaq bin Ali Rahawi, who wrote the *Conduct of a Physician*, the first book dedicated to medical ethics, and al-Razi; Jewish thinkers such as Maimonides; Roman Catholic scholastic thinkers such as Thomas Aquinas; and the case-oriented analysis (casuistry) of Catholic moral theology. These intellectual traditions still continue today in Catholic, Islamic, and Jewish medical ethics.

In modern times, five main reasons have been constitutive for the birth of a discipline of biomedical ethics expressed succinctly by Isaiah Berlin²:

I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not other men's act of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes which are my own, not by causes which affect me, as it were, from outside. I wish to be

somebody, not nobody—a doer, deciding, not being decided for, self-directed and not acted upon by external nature or by other men.

This is in stark contrast to the African philosophy of Ubuntu, which basically says that one's humanity is dependent on the appreciation, preservation, and affirmation of the other person's humanity, as was well expressed by Dzobo in 1992³: “*We are, therefore I am, and since I am, therefore we are.*”

Before we go into the discussions of what constitutes African ethics, we need to clarify the use of that term in this context. The entire African continent cannot be said to have identical cultural ethics. However, ethical themes and values are similar “in their essentials, as African cultures, metaphysics, attitudes are at least very similar”.⁴ For the purpose of this chapter, the generalisation to African ethics based on similar African cultures is therefore acceptable. This applies with the exception of North Africa, where cultures and ethics are more in line with Islamic injunctions.

African ethics (also known as African traditional ethics) is communal in outlook; it defines moral precepts and values that Africans abide by consciously or unconsciously in their day-to-day living. Those moral precepts are defined and founded on communal values. Hence, Africans have the saying that “one can only dance well when one dances in line with the drum beat of the community”. This means that what is considered good or bad is what the community considers as such. For instance, amongst the Esan people of southern South Nigeria, *ebeme* and *agbonsi* (the good and worthy life) are understood in terms of the communal good. This means that the realisation and actualisation of the self is expected to be through and within the community and not outside of the community.

However, this does not mean that the self is suppressed in favour of the community. Rather, it means that in the actualisation of the self, the community should and indeed must be taken into consideration. As a result, community recognition and appreciation are highly important in African communities, and a member cannot be recognised by the community if his or her moral values are personal and subjective and at variance with those of the community. This is important, as “morality in African traditional thought is essentially interpersonal and social, with a basis in human well-being”.⁵

African ethics is based on a communal and utilitarian foundation. In traditional African societies, the good aims for greater benefits to the generality of the community, and is therefore not based on religious or divine injunctions as such. “The gods may only be relevant when it comes to the use of divination and application of sanctions, that is, if a member of the society errs against the norms of the society and he is unrepentant”.⁶ This belief implies that the consequences of one's actions rather than the alignment of such action with his or her religious faith determine praiseworthiness from a community perspective.

Western-Style Medical Ethics

Let us first look at the Western style of medical ethics and at the five important constitutive points and discuss how we could apply these principles to an African context:

1. growth of the middle class with its new value system of individualism, utilitarianism, and a culture of consumerism;
2. disenchantment of the world, leading to a decline of a reliance on myths, religions, and ideologies, leading to an increased rational and practical approach to life;
3. increased influence of feminism, giving rights to women;
4. fragmentation of society into different spheres, such as human rights, morality, religion, politics, jurisdiction, family, school, etc. as well as the super-specialisation within medicine; and
5. new belief or ideology of a technoscientific progress into utopia.

Such faith in a utopia achievable by technoscientific progress boosted the scientific enterprise enormously. Such scientific discoveries were not only embraced with enthusiasm, but created an equal amount of controversy. Medical progress (e.g., haemodialysis becoming possible with the development of the arteriovenous shunt, or techniques of cardiopulmonary resuscitation), together with the perennial problem of limited resources, raised a set of very difficult considerations, such as who should live, who should die, and who should decide?

Such positive development was not without serious abuse of physician power, as is highlighted by the Tuskegee study. One of US president Bill Clinton's more convincing apologies in recent times was that made on 16 May 1997, for the infamous Tuskegee Syphilis Study. From 1932 to 1972, hundreds of poor black farm workers with syphilis were deliberately left untreated, with the supposed goal of studying the natural history of the disease. Participants received free food and transportation to encourage them to join a study they were told was aimed at curing their "bad blood". In fact, government officials went to inordinate lengths over the decades to ensure that these men received no treatment at all, even after the discovery of penicillin. It is inexplicable that such a study went on for more than 40 years (1930–1970), even after a treatment for syphilis was found. It is unlikely, even after the Nuremberg Code and the Universal Declaration of Human Rights (1948), that people would be safe from unethical research practices.

Recent research on male circumcision as a prevention of human immunodeficiency virus (HIV) (3 randomised controlled trials (RCTs) in South Africa, Kenya, and Uganda) requires assessment of the research outcome for the female partners of those men who were HIV positive at the time of circumcision, to realise that a Tuskegee could be repeated. It has been suggested that the female partners of the HIV-infected men who were circumcised had not been informed that they were part of a study. The outcome of the study as reported by Dr. Wawer,⁷ showed that the HIV incidence of those female partners increased by 60% over a period of two years.

Informed Consent

In the Western world, a specific style of conversation between the patient and doctor has developed whereby the patient is encouraged to take a more active, informed position within the decision-making process.⁸ Some physicians, however, still point out that they can solve all difficult questions without discussing them with the patient or the patient's proxy by relying solely on their own professional expertise. It is important, however, to be aware that professional expertise is not without value judgements. Therefore, the physician-patient relationship has been described as an often-conflicting power dichotomy. An extreme on the side of patient autonomy denies any room for physician decision making.⁹ Such an extreme approach had been called the informative, or engineering, model of the patient-physician relationship, whereby the "physician's role is to disclose factual information about

diagnosis, prognosis, treatment options, etc. A patient's role, on the other hand, is to inform his or her physician about values and preferences concerning treatment".¹⁰ The assumption here seems to be that all value-judgements should be the patient's responsibility. Such an assumption, however, is illusory because value-free information is impossible to attain.¹⁰

More important are five consequences of this informative model. (1) It impoverishes the patient-physician relationship by discouraging doctors from empathising with their patients because such empathy is considered undesirable and might negatively influence the doctor's professional attitude. (2) It stops any discussion between the patient and doctor from the beginning, preventing doctors from questioning perceived strange and irrational patient treatment demands and preferences. (3) It prohibits physicians from sharing their acquired personal experiences and moral beliefs. (4) It completely misinterprets patients' preferences as ready-made and given; it does not acknowledge or allow patient preferences to develop or to be adjusted during the course of illness and therapy. (5) It deals with the patient-doctor relationship and their respective preferences and attitudes as if there were no overall, encompassing societal good to be considered; it completely ignores that both patient and doctor have their preferences imprinted by society and need them to be adjusted from time to time by the overall good of society.

Paternalism, as the opposite of the informative model, often involves some form of interference with or refusal to conform to patients' preferences. "Paternalism, then, is the intentional overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefitting or avoiding harm to the person whose will is overridden."¹¹

Within the African context, paternalism has hardly been contested. It is still common and easy for physicians to ignore and neglect patient autonomy. Apart from the cultural divide and lack of exposure to each other's value systems, there is an underlying assumption that medical knowledge and technology could be too complex to understand for patients in general, and African patients in particular. Patients easily develop unrealistic expectations of modern medicine and adopt a cowed role, trusting their doctors' expertise unconditionally.

We suggest that the dichotomy between autonomy and paternalism be abandoned altogether to favour a model of deliberation wherein patient and physician interact, share and finally make the decision together. Both parties ought to accept moral responsibility to arrive at a decision. Such a solution is more than just the consensus of two positions and suits the African context and philosophy of Ubuntu. The deliberation model points to the urgent need for democratisation of Western medicine and its institutions.

Giving informed consent for a procedure on a child has its own set of problems. It is morally advisable, if a child has the cognitive and emotional maturity to understand the situation, that his or her assent should be sought as well as the consent of the parents or legal proxy. Parents, however, do not have the right to refuse or give consent to surgical procedures if doing so would be detrimental or of no immediate benefit to the child. Paediatric surgeons should be familiar with each country's individual legislation.

The ethical justification of informed consent is respect for the patient's and family's autonomy and for the right of the patient or proxy to make informed decisions. Informed consent is, therefore, one of our main duties as paediatric surgeons, and this usually means obtaining parental consent.

Informed consent includes a three-tier cascade, each step presupposing the previous one.

1. *Determination of the patient's competence to give consent:* Competence is a prerequisite to be able to give informed consent. A competent patient needs to be able to grasp the essentials of what is explained, to think rationally and logically, and to come to an

apparent rational decision. Competence can be limited according to the circumstances of the patient, both intrinsic (mental) and extrinsic (specific law or rule, such as incarceration or institutionalisation).

2. *Provision of adequate information:* Information forms the foundation upon which the competent patient can make a decision. Such information must include a full explanation of the proposed techniques as well as information about the chances of success, incidence of complications, risks involved, available alternatives and their relative risks and complications, costs involved, and the role of each member of the surgical team. Risks include those inherent to the procedure and disease, compounded by host risks relating to underlying disease and comorbidity, as well as those inherent to the particular environment where surgery is to be performed (e.g., inexperienced surgeon, new procedure, and so on).¹¹

3. *Decision making:* Based on the information supplied and the patient's competence, the patient or proxy can make a voluntary decision without coercion to undergo (or defer) a treatment. The patient or proxy should be informed of the consequences of that decision and his or her right to withdraw such consent at any stage and to seek a second opinion.

Within clinical practice, the process of informed consent presents several inherent problems:

1. *The timing of obtaining consent:* Under ideal circumstances, the taking of informed consent should occur a few days prior to surgery to facilitate unhurried, uncoerced decision making; to obtain more information; to discuss the matter with family members; and to review the decisions made. In the case of an emergency, this might be impossible, but this does not absolve the surgeon of the responsibility to obtain informed consent to whatever extent possible. We address the subject of informed consent during emergency surgery later in this chapter.

2. *The complexity of the disease and its modern surgical treatment:* Paediatric surgery has become a mature discipline in its own right,¹² and the technological options have been growing. Not all options are currently available in some African countries due to resource constraints. Some patients might therefore decide to have their elective surgery performed in another country.

3. *The extent of information necessary:* Any information that the patient might need, or reasonably use, to make a decision is appropriate. As a general guideline, the more serious a condition and the higher the probability of risk and complications, the greater is the need to inform the patient. However, forcing unwanted information onto a patient could cause unnecessary anguish and could be interpreted as psychological battery.

4. *Risk disclosure:* A reasonable question is whether it serves the patient's interest to disclose all complications and how much patients actually understand the statistics. The ideal would be to provide institutional outcome figures. As an alternative to quoting actual figures of complication risks, a verbal scale from very high, to moderate, to very low, to negligible could be used.

5. *The use of aids and pamphlets:* The South African Health Professions Council (HPCSA) guidelines advocate the use of "up-to-date written material, visual and other aids to explain complex aspects of . . . treatment where appropriate and/or practicable".

6. *Who should take the consent?* Without a doubt, the surgeon doing the procedure is the best person to obtain consent. The surgeon should inform the patient about the risks and complications that could arise from the procedure.

7. *Costs:* It is the duty of the surgeon to inform the patient or parents/caregivers about the costs to be incurred and how they are expected to pay.

8. *Research:* These points do not apply fully to research on patients.

In summary, the patient's cooperation is important before performing any procedure. The aim is not to impress or dominate, but to inform. The surgeon should use understandable and down-to-earth language, tapered

to the level of the patient's and parents' understanding, to discuss:

- all invasive procedures and those realistically expected;
- all common and serious complications; and
- all options and alternatives.

The basic idea of the process of informed consent-taking is that the surgeon should have made as sincere an attempt as possible to come as close to the ideal, given the limitations of time, language, and cultural difficulties.

HIV, Ethics, and the Paediatric Surgeon

Why is human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) such a major issue for society and for medicine? One of the reasons is the sheer magnitude of the pandemic, especially in sub-Saharan Africa. The vast majority of affected people are poor and thus easily subjected to discrimination. Another is the fact that it is a sexually transmitted disease, and as such is viewed as morally reprehensible. People affected by HIV/AIDS are often seen as blameworthy, and AIDS is viewed as punishment for moral transgression. Grayling writes that AIDS is seen as "evidence of God's wrath, justly provoked by our sins".¹³

HIV is different from other epidemics because it affects mainly young adults and has a long incubation period with a very high mortality. Additionally, the HIV outbreak has occurred at a time when medicine is very technology driven, and advances in medical and surgical treatment may expose health care workers (HCWs) to great risk from blood and other body fluids.¹⁴

The surgeon is a unique medical professional in that "any operation performed harms before healing.... Consequently, by striving to minimise this necessary temporary injury to the patient while maximising the therapy's curative potential, surgeons have forever engaged in ethical deliberations".¹⁵ The Cambridge Textbook of Bioethics describes the surgeon as being the patient's advocate "in the purest sense"¹⁵ because the surgeon protects the patient's values as well as his or her physical health.

In the context of HIV, it is important to consider whether surgery poses an additional risk to the HIV-infected person, and to weigh the relative risks and benefits.¹⁶ There is also the issue of personal risk to the surgeon, and whether the HCW can refuse to treat an HIV-infected patient. This hotly debated subject in the ethics literature in the late 1980s and early 1990s has become a nonissue with the advent of antiretroviral treatment (ART) and postexposure prophylaxis.¹⁴

By virtue of its high prevalence in Africa, the surgeon inevitably will encounter many moral dilemmas associated with HIV/AIDS. In this chapter, we address the following ethical dilemmas in the context of HIV/AIDS and medical care: HIV testing and informed consent; confidentiality, privacy, and the duty to warn; and justice, discrimination, and access to ART. We also touch on the debate around the ethics of neonatal circumcision as prevention for HIV.

HIV Testing and Informed Consent

Usually, in-depth discussion and consent for blood tests is not required. However, HIV historically was considered to be different because treatment was not available early in the AIDS epidemic, and HIV was associated with psychosocial risks and discrimination with regard to employment and access to health insurance.¹⁷ International and national guidelines state that HIV testing should be done only with the informed consent of the patient (if old enough to consent) or the parent, and after pretest counselling. This approach to HIV testing, together with respect for confidentiality, constitutes a strict advocacy view of the rights of the individual. The issues of consent in children, particularly in the African setting, have already been addressed in the first part of this chapter, and they also apply here. The age at which a child can consent to HIV testing depends on the child's maturity and understanding. New legislation in South Africa places this age at 12 years. There is an increasingly

strong movement, both internationally and locally, to advocate for “opt-out” testing, where HIV testing becomes part of routine medical care unless patients refuse it. The problem for Africa is that antiretroviral therapy is not universally available, making it difficult to legislate “opt-out” testing. The current approach is to recommend voluntary testing except in very limited emergency situations.

Confidentiality, Privacy, and the Duty to Warn

The stigma and discrimination associated with HIV/AIDS necessitate confidentiality and privacy of information. If privacy of medical information is assured, it is more likely that patients will be prepared to be tested, and it promotes patient autonomy and trust in the clinical relationship.

An important consideration for the paediatric surgeon is that a diagnosis of HIV in a young child implies, in the majority of cases, that the mother is HIV infected. This impacts on confidentiality regarding the mother’s status and relationships and gives rise to a set of ethical and moral dilemmas.

Conflict may arise in the clinical situation where HCWs demand to know the status of patients as they believe themselves to be at risk of being infected. This is of particular importance in the case of surgeons, who are at even greater risk of becoming infected due to the nature of their work. With the adoption of universal infection control precautions, however, the risk of HIV transmission should be minimised, provided the necessary resources are available.¹⁸

But what about HIV-infected HCWs? Do they also have a duty to disclose their HIV status to patients or to health authorities? Should this form part of the informed consent process? Disclosure may jeopardise HCWs’ ability to practice and their careers, and so the general guideline is that HCWs may continue to practise without disclosure, but with restrictions so as to avoid situations in which the patient may be at high risk of becoming infected.¹⁶

Justice, Discrimination, and Access to Treatment

The reality of medical practice in Africa is that it mostly occurs in resource-constrained environments. It is inevitable that distributive justice will play an important role in ensuring the fair distribution of these resources. Public policy dictates that those patients who would benefit the most should have access to ART, and that eligibility criteria are just.¹⁹ At the same time, people admitted to the ART programme are expected to be compliant; resistant viral strains have been identified in patients who have not been on ART.¹⁴ The rights of the individual to access therapy have to be weighed against the rights of the community put at risk by noncompliant patients. How does one manage a young child who is dependent on the caregiver for access to ARTs, but whose caregiver is not an adherent to therapy? Should the child be removed from the caregiver?

HIV-infected individuals have been subjected to discrimination in society as well as by the health care system.¹⁸ This discrimination results in patients being deprived of services and care, which may cause them to lose faith in the system. Children may be denied access to certain health services (e.g., intensive care or surgery) because of their HIV status. It is difficult for the individual surgeon unilaterally to make difficult decisions, and policymakers increasingly have adopted the approach of “accountability for reasonableness” to prioritise services.¹⁶

Neonatal Circumcision for the Prevention of HIV

A full discussion of circumcision to prevent HIV is beyond the scope of this chapter. Three studies from Africa have demonstrated a protective effect of circumcision against heterosexual HIV acquisition in adult males, and this finding has been extrapolated to a recommendation to perform mandatory neonatal circumcision in sub-Saharan Africa.²⁰ The argument that “newborns are extremely resilient and are programmed for stress” to support the neonatal timing of circumcision²¹ does not take into account the ethical issues surrounding the removal “of healthy tissue from patients who are unable to consent to the procedure”.²² Extrapolating the

weak protective effect in a selective adult population to infant circumcision without any supportive data²³ may not be appropriate.

Informed Consent during Emergency Operations

Among the several legitimate exceptions to the right of informed consent are public health emergency, medical emergency, the incompetent patient, patient waiver of consent, and therapeutic privilege.²⁴ When immediate action must be taken to prevent death or other serious harm to the patient, the emergency exception mandates that appropriate care not be delayed.^{24,25} Informed consent under this condition is based on the legitimate presumption that the child or legal proxy would allow treatment if the opportunity existed, so consent is implied. The exercise of the emergency exception imposes responsibility on the paediatric surgeon to be reasonably certain that immediate intervention is essential to preserve life or to prevent serious harm to the child. In addition, the paediatric surgeon must reach the judgment that treatment cannot be safely delayed to obtain informed consent.²⁶

Consideration of informed consent during emergency surgery might be met with some cynicism because the imperative to save life is seen as overriding patients’ autonomy. Surgical emergency creates a special challenge insofar as decisions must be made in a relatively short period of time. Submitting a child to emergency surgery is one of the most profound and emotionally exhausting tasks most parents will encounter. Added to the stress of sudden illness and the distress caused by pain or other acute symptoms in their child, parents may have little time to grasp the important information required to give an informed consent. However, only the occasional situation (e.g., haemorrhagic shock) justifies the emergency exception. In the majority of children undergoing urgent or emergency surgery (e.g., appendectomy), there is quite often ample time for preoperative education of the family and informed consent.

In Western countries, a surgical emergency rarely absolves the surgeon of the requirement to obtain consent. We propose that African paediatric surgeons observe this practice as a moral and ethical necessity, even though they may not yet have a legal obligation to do so. If the parent(s) or the family members are not present, the surgeon can decide according to the best interest’s paradigm. Some hospitals will have their own regulations, such as that the superintendent can give consent to an emergency procedure as long as there is evidence that the staff has tried to contact the family members. Telephonic consent is acceptable.

Informed consent during paediatric surgery emergencies has been the subject of a detailed review, including practical guidance on the methods of preoperative education that can be adopted in the emergency surgery setting and areas in which further research might help to improve this important aspect of surgical care.²⁷

Informed Child Assent

Strictly speaking, only those patients who have appropriate decisional capacity and legal empowerment can give their informed consent. Under common law in most countries, the decision-making responsibility falls generally to parents or other surrogates. Because no one—not even the most well-meaning parent acting in a surrogate capacity—can always assure that the child’s best interests are being represented, the doctrine of informed consent has limited direct application to children.²⁸ Although informed permission given by parents does not satisfy the strict moral standards of the doctrine of informed consent, it is sufficient for ethical—and is often required for legal—purposes. In addition, older children and adolescents should be involved, to the greatest extent possible, in their own decision making. Depending on the circumstances, the *assent* of the paediatric patient should be sought, appropriate to their development, age, and understanding, and often in conjunction with informed permission from the parent or legal guardian. In many Western countries, the requirement for informed child assent has been codified, but in all cases, doctors should carefully listen

to the opinion and wishes of children who are not able to give full consent and should strive to obtain their assent. The consent/assent process must promote and protect the dignity, privacy, and confidentiality of the child and his or her family.

Conclusion

This chapter has addressed some of the ethical issues that the paediatric surgeon may encounter. The relationship is three-pronged: the child-patient, the decision maker (parent/caregiver), and the surgical team. It is important that the surgeon be aware of the ethical issues and moral dilemmas influencing this relationship, and that the child's best interests remain paramount. In many African countries, resource constraints also play an important role; here the surgeon must weigh the risks and benefits of surgery to the patient and advocate for the patient where appropriate. There is also an obligation for the experienced surgeon to convey knowledge, skills, and values to other staff and to the public.

Evidence-Based Research

Table 13.1 presents an expert opinion on European guidelines regarding informed child assent.

Table 13.1: Evidence-based research.

Title	Informed consent/assent in children. Statement of the Ethics Working Group of the Confederation of European Specialists in Paediatrics (CESP)
Authors	De Lourdes Levy M, Larcher V, Kurz R
Institution	Ethics Working Group of the CESP, Department of Paediatrics, University Hospital Graz, Graz, Austria; University Clinic of Pediatrics, Hospital de Santa Maria, Lisbon, Portugal; Queen Mary's School of Medicine and Dentistry, London, UK
Reference	Eur J Pediatr 2003; 162(9):629–633
Problem	A report by a working group of experts assembled from several European countries providing paediatric health care practitioners with guidelines on informed consent and assent.
Intervention	Expert opinion.
Outcome/effect	Consent or assent is required for all aspects of medical care, for preventive, diagnostic, or therapeutic measures and research. The consent/assent process must promote and protect the dignity, privacy, and confidentiality of the child and his or her family.
Historical significance/comments	This report extends and clarifies similar guidelines issued by the American Academy of Paediatrics, Committee on Bioethics. ²⁸

Key Summary Points

1. Surgeons should be aware of the specific cultural, psychological, and ethical milieu to which the child and family belongs.
2. Practice should be guided by the ethical principles of patient autonomy, respect for persons, non-maleficence, beneficence, and justice.
3. African ethics is based on communal, rather than individual, values.
4. Informed parental consent should always be obtained before surgical procedures to whatever extent possible even in emergencies.
5. Informed child assent should be sought, as appropriate to the child's development, age, and understanding.

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