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Pregnancy termination in the case of an orofacial cleft: an investigation of the concept of reproductive autonomy

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Abstract

**Objective:** To describe ethical approaches to the issue of pregnancy termination after prenatal detection of cleft lip +/- palate.

**Results:** Gynecologists and cleft surgeons are sometimes confronted with the demand for a pregnancy termination after ultrasound detection of an isolated cleft lip/cleft palate. In this paper, we discuss different ethical theories and principles that can be applied to the dilemma at hand. We formulate recommendations that will respect the right to autonomy of the pregnant woman and at the same time acknowledge that a termination of pregnancy for a cleft lip may in most cases not be the best option.

**Conclusion:** The recognition of each person’s right to reproductive autonomy also entails that clinicians should make sure that prospective parents are provided with up-to-date and relevant clinical information.

Keywords
Ethics, prenatal diagnosis, pregnancy termination

Introduction

Consider the following scenario. A couple, man and woman, in their early thirties, visit their gynecologist: the woman is 20 weeks pregnant, and will have her 20 weeks ultrasound. During the ultrasound, it is discovered that the fetus has a cleft lip and palate. They are referred to the university hospital, for amniocentesis. No abnormalities were found on array-CGH. During the ultrasound at the university hospital, no other fetal anomalies are detected either. The couple goes home: two days later they inform their gynecologist that they want a pregnancy termination. They are sent, once again, to the gynecologist of the University Hospital, who, in term, asks the local Ethics Advisory Board whether this request for termination can be granted. What advice should the board give?

Pregnancy termination after ultrasound detection of cleft lip/cleft palate is a textbook bioethical dilemma. For some, it is the ultimate, and immoral, example for the search for a perfect child. For others, the desire not to continue with a pregnancy of a fetus with cleft lip +/- cleft palate falls well within the scope of reproductive autonomy. Surprisingly, in comparison with discussions related to the detection of genetic abnormalities in fetuses and even in preimplantation embryos, relatively little

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1 This case is an adaptation and amalgam of different cases the authors have met in their professional capacity, one as an orofacial cleft surgeon, and the other one as an ethicist serving on an ethics committee of a university hospital. During the writing of the paper and the prior discussions we never mentioned names or specific context of cases, but we found it necessary to point out that such cases do exist and are perhaps more frequent than expected.
literature has been devoted to this ethical issue. With this paper, we want to fill that gap. Using the Belgian and Dutch legislation as a starting point we will demonstrate that the issue of pregnancy termination after the detection of cleft lip +/- cleft palate raises some deeper ethical questions regarding autonomous choices that are as of yet unresolved in ethical discussions surrounding prenatal decisions. Moreover, future technological developments may complicate the issues even more. We contend that while we believe that reproductive autonomy and the duty to respect patients’ wishes is a principle that should be upheld, this does not mean that the request is not problematic or that one should fulfill it without further ado. We will point out that making an autonomous choice entails having a correct view on all possible options and life courses, regardless of prejudice. Therefore, we propose some guidelines.

Background and Legal Context
Prenatal diagnosis of orofacial clefts can be done from 15 weeks onwards. In most European countries, this happens at the 20 weeks ultrasound (Maarse et al., 2010). The detected clefts are of the type cleft lip +/-cleft palate. The detection through ultrasound of isolated cleft palate is difficult; this type of orofacial cleft is typically detected postnatally(Abramson et al., 2015). 90% of cleft lip +/- cleft palate is non-syndromic, as compared to 50% of isolated cleft palate. If during the ultrasound no additional anomalies are found, there is a low chance of genetic abnormalities. If in doubt, genetic screening can be done via amniocentesis (Maarse et al., 2012). This does not completely rule out associated anomalies or underlying genetic conditions.

Prenatal detection of orofacial clefts has certain advantages. Parents are prepared to the birth of a child with a cleft, which enhances the experience of giving birth. Treatment options can be discussed and planned before birth. Depending on the cleft type, children born with an orofacial cleft will face one or more operations in their first year of life. In case of a cleft palate, newborns may have feeding problems which can make breastfeeding difficult or unfeasible. Children with a cleft palate are more likely to suffer from middle ear ventilation problems, often requiring ventilation tubes. A cleft palate has an impact on speech development, and affected children may need speech and language therapy or occasionally further surgery to improve speech. In addition, children with a cleft lip +/- palate have a greater chance of needing orthodontic and orthognathic treatment and may opt for additional corrective procedures in adulthood(Worley, Patel, and Kilpatrick 2018). There is not much data on cleft lip/cleft palate as a an indication for termination of pregnancy worldwide. Preliminary evidence suggests that after the introduction of routine screening system for physical congenital anomalies was introduced by legislation in 2007 in The Netherlands, the termination of pregnancy in case of cleft lip/cleft palate remains limited, but the gestational age at diagnosis of CL ± P has decreased and the proportion diagnosed prenatally has increased (Ensing et al. 2014; van der Molen et al., 2011). However, the uptake of prenatal diagnosis in general has traditionally been low in The Netherlands compared to other countries(Gitsels - van der Wal et al., 2014). In some papers, it has been suggested that the overall decrease of the occurrence of cleft lip worldwide may be attributed to availability of prenatal screening and pregnancy termination(Dalben, 2009).
1996-2006 in the demographic region of Negev found a significant decrease in the occurrence of cleft lip among the Bedouin population. They suggest that this may be attributed to increased access among this population to prenatal care, although they also suggest that isolated cleft “is not in itself an indication for abortion”. Studies have suggested that in some countries a high number of pregnancies in which cleft lip +/- palate was detected were terminated, for instance in Israel where these are detected earlier in the pregnancy, at 15 weeks (Jones, 1999, 2002; Bronshtein, Blumenfeld, and Blumenfeld, 1996). Other studies suggest that “prenatal diagnosis enables counseling and a sense of preparedness for the majority of affected families and only rarely results in termination for isolated clefts.(Steinberg and Gosain, 2015)"

The prevalence of termination of pregnancy for orofacial clefts is influenced by the legal framework of the country. For example, in Ireland, termination of pregnancy is forbidden in most cases. Termination of pregnancy is legally allowed in Belgium up till 12 weeks, at the time of the writing of this paper. After that, it is allowed in case of proven severe and non-curable diseases in the fetus or danger to the health of the woman, and advice is sought from a second clinician. This is different from legislation of for example The Netherlands, where termination of pregnancy is allowed until 24 weeks of gestation. 24 weeks is considered the threshold of viability, after that the interests of the fetus, as it is viable, are thought to prevail. Hence, women who do not satisfy the requirements for pregnancy termination in Belgium can have a termination in the Netherlands, if they are less than 24 weeks of gestation. Women in the Netherlands, who are over 25 weeks pregnant, can opt to go to Belgium for termination of pregnancy. In Belgium, the registry of medical conditions for which a pregnancy was terminated in the second trimester is incomplete. From our own practice, and from anecdotal evidence, we know that the decision to end a pregnancy after the detection of an isolated orofacial cleft is rare, but that it does happen. This means that some practitioners do interpret an orofacial cleft as in the category of ‘severe and untreatable condition at the moment of diagnosis.’

We will now leave the legal discussion aside and we shall focus on the ethical discussion surrounding termination of pregnancy in the case of non-syndromic cleft lip. The juxtaposition of the Belgian and Dutch legislation is useful however, to confront the reader with their own moral intuitions: in the Dutch case, it is in principle allowed to terminate a pregnancy before week 24, even for cleft lip +/- palate. In the Belgian situation, some would argue that cleft lip +/- palate does not fall into the category of severe and untreatable conditions. However, given the vagueness of the law, this can be interpreted in many ways and termination of pregnancy for cleft lip +/- palate does occur in Belgium. Although many ethicists and clinicians, including ourselves, will uphold the right of women to decide about procedures on their own bodies (the right to bodily integrity), we also acknowledge the intuition that for many, an isolated cleft lip +/- palate may feel like a medically futile reason for pregnancy termination, especially given the state-of-the-art of plastic surgery in the field. In what follows, we explore these intuitions, and formulate recommendations that will respect the right to autonomy of the pregnant woman and at the same time acknowledge that a termination of pregnancy for a cleft lip may in most cases not be the best option. We do admit that this discussion is mostly applicable to the Western context and that outcomes, and even access to surgery are not universally good and attitudes to children born with a cleft vary by culture and region.
The ethics of pregnancy termination for orofacial cleft

When dealing with ethical discussions surrounding prenatal screening, also in the case of cleft lip +/- palate, several ethical principles and moral theories can be considered: first, there is the issue of the moral status of the embryo and fetus, second, we may approach the question using a virtue ethics approach (being a good parent or a good medical professional as a virtue). Third, we may consider Julian Savulescu’s principle of reproductive beneficence and fourth, we may stress the importance of reproductive autonomy. Indeed, discussions on pregnancy termination have often centered around the moral status of fetus. In fact, considerations regarding the moral status of the fetus have been influenced by religious convictions regarding personhood, but are also used by secular scholars to draw the line as up to which point termination of pregnancy is morally allowed. For example, the Dutch law draws a hard line at the point of viability, which they have set at 24 weeks. In this paper, we shall not give a systematic overview of religious views and considerations, although we acknowledge that personal religious views are a good reason why clinicians may refuse a request for termination of pregnancy or why termination of pregnancy is never an option for certain parents.

Technological advances, virtue ethics and the status of the unborn child

The discussion on the status of the unborn fetus does shed some light on the issues related to the dilemma at hand. By limiting the time frame in which a termination of pregnancy is allowed, legislators and ethicists alike suggest that in these decisions there is a conflict between the right of women to decide on their own bodies and the rights of the fetus to be born. The rights of the women are then inversely related to the right of the fetus to live, and the latter right gains more prominence the further the pregnancy progresses. Of course, discussions regarding the exact starting point of viability and the point at which a fetus becomes a patient to be protected and cured are tightly linked with medical technologies. It may soon be possible to keep fetuses alive earlier than the 24 weeks that is commonly considered, also for example in Dutch legislation, as the threshold of viability. We will not explore these issues in more depth in this paper, but they are a prime example of how ethical deliberation is never finished, but always done in the context of what is technologically feasible. Technological advances in ultrasound technology may in itself raise new questions. In principle, orofacial clefts can be detected as from week 15, and there is some evidence that in countries that do screening at 15 weeks the rate of termination for the condition is higher than in other countries. Hence, were the ultrasound resolution to be increased even further, as to allow the detection of the cleft much earlier in pregnancy, this may lead to more terminations. If we object to pregnancy termination of a fetus that is near viability because of the increased rights of this fetus to be born, many would suggest that the objections are far less valid when the fetus is younger.

Some would intuit, however, that termination of a pregnancy for cleft lip +/- palate is immoral, even if we could detect it earlier in pregnancy. This intuition may be based on their conception of what it means to be a good parent. In this reasoning, being a good parent is accepting children as they are, especially if they have correctable anomalies. Such virtue ethics approach is probably close to what some clinicians will intuitively feel when confronted with the question. However the problem with virtue
ethics is that it is difficult to lay down universally valid virtues, let alone agree upon the interpretation of the virtues at stake here. Parents requesting termination may very well feel that it is exactly because they are good parents, to the child or to already existing children, that the termination is the right thing to do. Also, virtue ethicists stress the importance of education for the development of a virtuous character: becoming virtuous is a process that takes time and that does not happen in a void. What it means to be virtuous is specific to a specific situation, and requires a sensitivity to a particular context. It thus seems counterintuitive to force parents, by not giving them access to a termination, to be virtuous and carry the pregnancy to term, as virtues are exactly things that we cannot force people to adopt (Manninen, 2015). As such, they differ from duties. A virtue ethics approach is valuable to take into account, however, when thinking about the role of the clinician. It may not be able to give us an exact answer to the dilemma at hand, but being a good clinician or ethicist does not only entail applying laws or general principles, but listening carefully at the questions that patients raise, and being sensitive to specific contexts of requests.

The principles of procreative beneficence and procreative autonomy
In fact, some ethicists have adopted a completely different approach and have stated that, if possible, parents should make sure to have a child whose life is expected to go best. In such utilitarian reasoning parents have reasons to adhere to the principle of procreative beneficence. This principle is often quoted in the context of preimplantation diagnosis and relies upon the idea that if selection is possible you should choose the best. The reasoning, so it goes, is that if you have several embryos available in vitro, and you can select, based on genetic profiles, the embryo whose life is expected to go best, parents have a duty, or at least have good reasons, to choose that one (Savulescu, 2001; Julian Savulescu, 2007). It may seem straightforward to pick out embryos without severe congenital diseases, but strict adherents of the principle will also make no distinction between medical and non-medical information: Julian Savulescu, for example, has argued that if you could pick an embryo with an IQ of 140, you should choose that one. There are several problems with this reasoning. First, although choosing an embryo free of mutations may make sense in the case of embryo selection, where there are many available, it is far more difficult to apply it to prenatal diagnosis. One may suggest that women carrying a fetus with a specific condition, provided that she has good fertility and is still young, should preferably terminate and try to conceive a child whose life may go better, but such suggestions seems far removed of the lived experiences of the pregnant women themselves. Moreover, in the case of genetic information, the idea that genes alone can determine whose life will go best seems naïve. Although people would assume that the embryo with the IQ of 140 has been given a nice head start in life, this need not necessarily be the case as we do not know anything of her future hopes and dreams (Parker, 2007). The same goes for anomalies that can be viewed on the ultrasound: the mere fact that a fetus has an orofacial cleft in itself does not predict outcomes of wellbeing. The fact that we cannot foresee the actual consequences of the actions that we undertake in order to achieve a certain outcome, is one of the drawbacks of utilitarian thinking. This is especially the case if we are talking about the values and lived experiences of future human beings.

One of the most quoted principles both with regards to ethics of reproduction and in legal documents is that of reproductive autonomy or procreative liberty. This principle implies that people, especially women in this case, have the right to choose for themselves whether they want to reproduce or not. In
the interpretation of Robertson, this also means having the right to decide for yourself which characteristics you want in your children, provided that these characteristics are in themselves not harmful (Robertson, 1996).

In discussions about reproductive freedom and the extent of reproductive freedom, often the case of an unwanted pregnancy is taken as an example. However, we believe that the case of pregnancy termination for fetal abnormalities should be seen in a different light, and this light may also give us some guidelines as to how to solve the dilemma. In fact, the question at hand here is about the termination of a wanted pregnancy. Hence, the reasons why a pregnant mother considers termination of pregnancy are different from the case of an unwanted pregnancy. In principle, we may assume that the reasons to terminate the pregnancy have to do with concerns regarding the welfare of the child or the impact of the disability of child on the family, for example if there are other children that require care or perhaps even if the parents have busy professional lives and may consider the visits to the hospital and the subsequent care of the child unmanageable. Although especially the latter may go against moral intuitions of many about what it means to be ‘a good parent’ from a virtue ethics perspective, it may still fall very well within the limits of the reproductive freedom of the parents. In the context of prenatal screening, the principle of reproductive freedom, or procreative autonomy, goes hand in hand with that of bodily integrity or bodily autonomy: only the pregnant woman herself can decide on the fate of the fetus, and no third party can force her to undergo tests or either continue or abort a pregnancy. Although this right to bodily integrity and reproductive autonomy has been questioned lately in certain countries, we believe that hollowing this right, and putting restrictions on the decisional capacity of women is unethical. However, what is crucial is that exercising autonomy presupposes having been given all and adequate information to be able to make a well-informed choice.

In the context of prenatal counseling after genetic screening, the principle of non-directive counseling has been quoted. Such principle empowers the patient to make important decisions by imparting knowledge and being given the power to make his or her own decision (Saal, 2002; Szasz and Hollender, 1956). Howard Saal has applied this principle of genetic counseling also in the case of cleft lip +/- palate: it is not the task of the clinician to impose her own values, which, he contends, may be influenced by the experience these clinicians have with children with orofacial clefts under their care. A clinician, he argues, should gain insight in the patient’s and family’s cultural, social, moral, and religious backgrounds, and provide the necessary information they need to make an informed decision that fits their background.

Although the concept of autonomy and of non-directive counseling have been questioned on philosophical grounds (Clarke, 1991) (can anyone be truly anonymous? Or is non-directive counseling a theoretical and even sterile concept that neglects the fact that what patients with a request for information actually want is guidance?) we think that it at least can function as an ideal of what prenatal counseling could be, also in the context of prenatal detection of orofacial clefts. As such, it is still the best basis for policy making.

Having described the theoretical background of the principle of reproductive autonomy and non-directive counseling, we now come to some caveats. Ethical principles often seem abstract and legalistic, and far removed from the actual feelings and motivations of at least two stakeholders: existing children and adults who were born with an orofacial cleft, and the actual pregnant women making the decision.
Indeed, disability rights scholars, often with first-hand experience of living with a certain condition, have questioned the current paradigm of prenatal testing, suggesting for example that the availability of such techniques, specifically in the context of decisions regarding termination, sends a discriminatory message to people living with, or having lived with the condition. It may seem that disability rights clash with the above mentioned women's rights of bodily integrity. However, feminist disability scholars such as Shelley Tremain have argued that this need not be so: rather than increasing reproductive choice, existing technologies may direct women into seeing a pregnancy termination as the only valid option, by its mere existence. This is far removed from the original idea of prenatal diagnosis as enabling women to make their own informed choice. It is possible that women consider having a child that requires extra care in their first year as an unbearable burden in a society that is already demanding in many other aspects. Or their vision on what it means to have been born with an orofacial cleft is clouded by their own experience of being bullied with the condition some decades ago. They may also be shocked by certain images they see online. Some of these concerns may be alleviated by being given up-to-date information about treatment options and results. Hence, we agree with disability scholars that being able to make an informed decision is not only related to being given the right information, but also by a society offering alternative possibilities.

Some further directions

So, what should one do when a woman requests that a pregnancy with a fetus with an orofacial cleft is terminated? Some clinicians will feel this is a valid request, others will not want to comply with it. At least, what one should do is make sure that this is a truly autonomous choice, based on correct assumptions of what the condition is and what it will entail. Although we acknowledge that pregnancy termination for cleft lip +/- palate is ethically problematic for many, we also contend that for now, non-directive counseling is arguably the best of all options, and that there should still be some room for pregnancy termination to be allowed even in the context of cleft lip +/- palate, if this decision is well informed and heartfelt. Nevertheless, we argue that pregnancy termination for non-syndromic cleft lift/cleft palate is something that preferably should not occur, and policies should be put in place in order to make the choice to continue the pregnancy as natural as possible. This need not and should not include nudging women to continue the pregnancy, but can be achieved through other means. On the one hand, and this is beyond the capacity of the individual clinician or professional organization, this requires that we continue striving for a society that is accepting of people with facial features that are not standard. It also implies that parents with children with extra care needs receive all support that they need, so that the lack of support is not in itself a reason for which a wanted pregnancy is terminated. On the other hand, professional organizations of orofacial cleft surgeons and gynecologists could cooperate to set up an infrastructure and information flow that will make sure that such decisions are taken in the most optimal way. More specifically and non-exhaustively we suggest the development of a joint policy in which at least the following elements are present:

-Gynecologists should de facto refer their patients who are pregnant with a fetus with an orofacial cleft to a specialist orofacial cleft team, not only those who want to continue the pregnancy. This should be a requirement for any such pregnancy, before any decision is taken.
Realistic and accurate explanations should be given to these parents by the team’s psychologist and surgeon including the esthetical, functional and psychological consequences of the cleft, the treatment plan and its outcomes, and the possibility of prenatally undiagnosed additional anomalies—Realistic and accurate explanations should be given to these patients regarding the pregnancy termination itself and the psychological and physical consequences of a late term pregnancy termination.

- Preferably, specialized information kits should be made containing information about what to expect regarding clinical care and prospects in the first years of infancy and beyond.
- In countries or regions where such counseling is not feasible, the cleft lip/cleft palate team should organize educational sessions for gynecologists on how to counsel these pregnant women regarding treatment options and prospects.
- Each hospital should at least have one gynecologist trained to counsel cleft lip/cleft palate pregnancies.
- This should be done within the spirit of nondirective counseling and without pressuring or excessive nudging of the woman facing a difficult choice.

If we go back to the original ethical dilemma, we can conclude that, of course within the country-specific legal constraints of pregnancy termination as such, we cannot absolutely forbid gynecologists to carry out a request for termination on moral grounds. That would imply that the woman is forced to carry a baby to term that she may not want. However, recognition of each person’s right to reproductive autonomy does not imply that we should not make sure that this decision is taken with the necessary precaution. The entire procedure should of course be done with respect for individual values and reasons of women or couples. In any case, policies must be put in place in order to ensure that the orofacial cleft team does not only speak to women pregnant with a fetus with an orofacial cleft when the decision to keep the fetus has already been made.

References


