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PRENATALLY DIAGNOSED FOETAL MALFORMATIONS AND TERMINATION OF PREGNANCY: THE CASE OF LEBANON

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Keywords
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ABSTRACT
Termination of pregnancy (TOP) is offered in many countries, for foetuses prenatally diagnosed with congenital malformations that are deemed incompatible with life or that are associated with a high morbidity. In Lebanon, a middle income country where religion plays a focal role, the law prohibits any form of TOP unless it is the only means to save the mother's life. It is the contention of the authors of this article that even if the foetus is a person, if it were medically revealed that there is a substantial risk that the newborn will suffer severe physical abnormalities that will cause it to be seriously handicapped; it is morally acceptable to terminate the pregnancy. Hence, TOP carried out for these indications is justified in the interest of the foetus and the child. Whatever the status of the foetus is, once born, it will become a full-fledged sentient being with all that this entails. When given the option of starting an existence, this person-to-be has the right to a minimum that allows him/her to enjoy a relatively good quality of life. Today, Lebanese obstetricians are confronted with the burden placed on them under the law to refuse TOP, or, when performing them, to forge records or deny having done them. This is why we strongly believe that the Lebanese policy on abortion should be amended.

INTRODUCTION

> *To be, or not to be: that is the question-*
> *Whether 'tis nobler in the mind to suffer*
> *The slings and arrows of outrageous fortune,*
> *Or to take arms against a sea of troubles,*
> *And by opposing end them?*
> *(Hamlet: Act 3, Scene 1)*

A 44-year-old primigravida with primary infertility was diagnosed at 16 weeks of gestation as having a foetus with multiple congenital malformations including holoprosencephaly (severe structural abnormality in the brain), cleft lip, deformed nose (proboscis) and polydactyly. Karyotype revealed a normal karyotype. The patient was counselled about the bad prognosis: a high risk of mortality within the first year of life, profound mental retardation, failure to thrive, seizures and visual and hearing deficits. Termination of pregnancy (TOP) was not offered to the family and baby Z. was born and is currently one month old in the intensive care unit. At this point, the following question arises: should children with severe and debilitating physical deformities be allowed to live?

Consider a child with Tay-Sachs, a fatal disease caused by the lack of the enzyme hexosaminidase A. The illness has a genetic origin and although newborns who suffer from infantile Tay-Sachs look healthy, they have what Arras calls a 'decidedly grim' life,[1] full of suffering and pain – eventually. The illness leads ultimately to total paralysis, blindness and death.

Indeed, there continues to be a lack of universal agreement on what constitutes the minimum requirements for decent living. It is equally true that different people might hold different opinions on what that minimum is. Yet, it remains a fact that before embarking on the path to

[1] J. Arras. AIDS and Reproductive Decisions: Having Children in Fear and Trembling. *The Milbank Quart* 1990; 68: 353–382.

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parenthood, prospective parents should ask themselves whether the life that they are begetting will be one that satisfies the minimum requisites for decent living or one with very low quality, clouded with agony and pain. Steinbock and MacClamrock proposed the 'principle of parental responsibility' which states that 'it is wrong to bring children into the world when there is good reason to think that their lives will be terrible',[2] while Purdy, concentrating on the example of Huntington disease, raised the issue of whether it is 'wrong to have a child because of genetic risk factors.'[3] Similar concerns are surfacing in Lebanon, a country where abortion is prohibited in general, yet widely but secretly, practiced.

BIRTH DEFECTS

The use of depleted uranium (DU) on Lebanese soil is another reason that makes one worry (a myriad of probable resulting birth defects are looming in the future). Should the policy remain oblivious to what *is* happening and to what *should* happen? Put differently, *ceteris paribus*, is it morally permissible to bring to life, children with severe physical defects? It is the contention of the authors of this article that even if the foetus is a person, if it were medically revealed that there is a substantial risk that the child, after birth, will suffer from severe physical abnormalities that will cause it to be seriously handicapped; it is morally acceptable to terminate the pregnancy. The point being that whatever the status of the foetus is, once born, it will become a full-fledged sentient being with all that this entails.

THE LEBANESE POLICY

In 1943, the Lebanese Penal Code banned abortion under all circumstances. Also banned, was the selling of substances,[4] or objects, intended for abortion purposes. According to Article 541, self-aborting a foetus or consensually having an abortion is an offense and can lead to imprisonment from six months to three years. Performing an abortion without the consent of a woman is deemed a crime and a consensual abortion that leads to the death of a woman, a felony. The Presidential Decree (No. 13187) dated October 20, 1969 reiterated the denunciation of abortion, but allowed therapeutic abortion if it were the only means to save the mother's life.[5]

In 1994, the Lebanese Law of Medical Ethics was first drafted, and later amended in 2004, with the articles 48–57 on the Rights of Patients and Informed Consent.[6] It stipulates that abortion is forbidden except when the pregnancy endangers the health of the mother and only after consulting with two physicians.[7] The law specifies that an informed consent is mandatory before performing the abortion except when the mother 'is in extreme danger and unconscious . . . even if the husband or next of kin object to it.'[8] If the personal belief system of the physician is against either indicating or performing an abortion, he can withdraw leaving the treatment of the pregnant woman to another specialized colleague.[9]

Notwithstanding the law and the severe restrictions on patients and physicians, the number of abortions, social and therapeutic, has been escalating in Lebanon. Some doctors perform abortions for the financial reimbursement and some because of fear that the procedure may be performed by untrained personnel, while others believe abortion is a woman's right of entitlement. According to an obstetrician in a tertiary care centre in Beirut, the Lebanese capital:

> [D]espite the law, we are giving patients with a 'fetal indication' the option of TOP. Examples include foetuses with chromosomal abnormalities and those with major malformations incompatible with life like anencephaly, prune belly syndrome and complex cardiac lesions.

Adnan Mroueh, Chairperson of the OBS/GYN department at the American University of Beirut Medical Center states:

> [I]n case the foetus is proven to be carrying severe defects incompatible with life, the options are presented to the parents, including the option of termination. Generally, this option is denied if the pregnancy is beyond 24 weeks of gestation; the stage of viability. This 24-week limit is also observed in countries where abortions are legalized. If the parents refuse, then the issue is closed and their desire is respected.

[2] B. Steinbock & R. McClamrock. When is Birth unfair to the Child? *Hastings Cent Rep* 1994; 24: 15–21:17.

[3] P. Laura. 1996. Genetics and Reproductive Risk: Can Having Children Be Immoral. In *Biomedical Ethics*. T. Mappes & D. DeGrazia, eds. New York, NY: McGraw Hill: 492–498: 493.

[4] Yet, prescription medications that lead to abortions are sold in pharmacies.

[5] Abortions in cases of rape are forbidden, although a fatwa (religious ruling) was lately issued to that effect from the Azhar.

[6] Syndicate of the Lebanese Order of Physicians. 2004. *Lebanese Code of Medical Ethics*. Beirut, Lebanon: Syndicate of the Lebanese Order of Physicians.

[7] Note that Lebanon is a country where religion plays a focal role. Prior to drafting ethical codes in medicine, the approval of religious figures from both Christianity and Islam are sought. Without the approval of both, an article cannot be ratified.

[8] All articles from the Lebanese Code of Medical Ethics are the authors' translations from Arabic; Syndicate of the Lebanese Order of Physicians, *op. cit.* note 6, p. 25.

[9] Ibid: 25.

Another obstetrician argues that one problem that arises is that women have almost no protection against malpractice in the event of complications secondary to TOP, with no professional oversight or safety regulations.[10] In addition, many women receive substandard care raising the risk of maternal mortality. Most physicians do not document the abortion procedures in the medical records for fear of being held accountable. In 2002, a study by Zahed et al. attempting to see the attitudes towards prenatal diagnosis and TOP, revealed that 80% of Lebanese women would seek TOP in relatively 'severe' conditions such as trisomy 21 (Down's syndrome) and 86.7% in case of 'severe mental retardation'.[11] Abortions are being performed frequently in Lebanon and the experts in the field believe that Lebanese women are constantly breaking the law to accommodate their actual needs. Policy makers are not willing to modify the law and at the same time are not enforcing its implementation. The Global Health Council Report of 2002 published estimates to the effect that the number of abortions in Lebanon between 1995 and 2002 amounted to 177,298.[12]

Prenatal tests intended to detect congenital malformations and chromosomal aberrations include sonography, first and second trimester blood test screening, amniocentesis and chronic villus sampling. These procedures are available and are being performed profusely in Lebanon. Indeed, there is nothing in Lebanese legislation on prenatal testing although prenatal testing for the purposes of gender selection is still being practiced by some centres. Nevertheless, no mention of such tests or their regulations exists in the Lebanese Code of Medical Ethics for fear of sliding into TOP. Specific ethical issues arise in this context of accessible prenatal screening and diagnostic services and restrictive abortion laws. If abortions are not permitted for foetal indications, then prenatal testing may create more dilemmas for the couple and the physician, as women are informed of a foetal abnormality, yet they are denied access to safe and legal TOP. According to Ballantyne et al., such scenarios give rise to three ethical problems: 'psychological distress, unjust distribution of burdens between socio-economic class and the social and financial burdens on families and society in caring for "unwanted" children who have serious chronic conditions.'[13]

Thus, one might wonder: what is the point of having the means to detect abnormalities *in utero* when there is a legal prohibition on abortion? One might also question whether healthcare professionals are playing a role in increasing unsafe abortions and affecting the health of the mother. Restrictive abortion laws do not seem to affect the overall rate of induced abortions; rather they increase the proportion of unsafe and illegal abortions,[14] more so in developing countries like Lebanon.[15] According to the World Health Organization, unsafe abortions account for at least 13% of maternal deaths worldwide. In addition, unsafe abortions are associated with morbidity including sepsis, haemorrhage and pelvic infection. In that respect, a duty falls on both physicians and health policy advisors to address this situation.

According to Zahed et al., acceptance of TOP in the case of mild or severe clinical conditions is comparable with that reported from European countries.[16] As indicated by Mroueh, during parliamentary discussions, when the draft law on medical ethics was being discussed in the Health Committee, the Committee agreed to a plan, according to which the option of TOP would be permissible if the foetus was proven to carry severe defects incompatible with life. However, when the draft law was taken up by the General Assembly of the Parliament, opposition to the draft was voiced by the Vatican envoy at the highest level of the Legislative Body. The Vatican envoy speaks for Catholics everywhere, and in Lebanon, this includes the Maronites. Because Lebanon is a country with multiple communities, respect and recognition of the views of each community is taken into consideration. If the Lebanese community feels that certain issues tend to contravene religious teachings and doctrines, such issues are not passed (an example is civil marriage). Thus, while working on a draft law on Premarital Medical Testing (in an effort to determine couples who may carry Thalassaemia traits), concerned personnel in Lebanon have to consult religious authorities to get approval in order to assure the Council of Ministers that no community has expressed any opposition to such legislation. While the Vatican encourages medical tests to remedy

[10] Z. Hankir. 2008. Denial Runs Through Lebanon: Reality Contradicts Lebanese Law on Abortion. *Now Lebanon* 21 January. Available at: http://www.nowlebanon.com/NewsArticleDetails.aspx?ID=27425 [Accessed 26 Aug 2010].

[11] L. Zahed, M. Nabulsi & H. Tamim. Attitudes Towards Prenatal Diagnosis and Termination of Pregnancy Among Health Professionals in Lebanon. *Prenat Diagn* 2002; 22: 880–886: 884; Note that the severity of the problems, including birth defects, visual and hearing impairment and other health problems, as well as the severity of the mental retardation vary greatly among affected individuals. Thus, whereas the condition can be considered 'severe' in some cases, it is not so in others.

[12] Global Health Council. 2002. *Promises to Keep: The Toll of Unintended Pregnancies on Women's Lives in the Developing World.* Washington, DC: Global Health Council. Available at: http://www.globalhealth.org/assets/publications/PromisesToKeep.pdf [Accessed 27 Jan 2009].

[13] A. Ballantyne et al. Prenatal Diagnosis and Abortion for Congenital Abnormalities: Is it Ethical to Provide One Without the Other? *AJOB* 2009; 9: 48–56.

[14] E. Rivera-López. Ethics and Genetics in Latin America. *Dev World Bioeth* 2002; 2: 11–20.

[15] World Health Organization (WHO). 2004. *Unsafe Abortion: Global and Regional Estimates of Incidence of Unsafe Abortion and Associated Mortality in 2000*. Geneva: WHO.

[16] L. Zahed et al. *op. cit.* note 11, p. 880.

birth defects, it indicts them if they lead to TOP. According to Pope Benedict, 'expected problems of disability of an unborn child cannot be a valid justifiable reason for interrupting a pregnancy.'[17] Conversely, assisted reproduction is forbidden by the Catholic Church, yet, the Vatican envoy did not veto the ratification of the corresponding law in Lebanon and consequently, in vitro fertilization is being done prolifically. Why is TOP, in case of foetal deformities, an exception? Although this falls beyond the scope of this article, it is an interesting issue to explore.

POLICY CHANGES?

Why should the Lebanese policy on abortion be amended? Two main concerns surface: first, it only allows for therapeutic abortions and this is so if, and only if, the pregnancy endangers the life of the mother and second, the policy has not considered the possibility of abortions in 'special cases' which leads to many abortions in actual practice. Special cases are, for the sake of our argument, cases where severe physical handicaps, incompatible with life, have been proven.

The political situation of Lebanon is also a factor that cannot be brushed aside. The country's war with Israel and the use of DU on Lebanese soil mean possible ensuing defects are a terrifying premonition, not a thought experiment. They happened in Iraq and some Iraqi physicians compare the birth defects that resulted from DU to those subsequent to the atomic bombings of Hiroshima and Nagasaki in WWII. They think that DU is responsible for a considerable increase in birth defects in the area. These physicians reveal pictures of infants born without brains, spines or sexual organs or with their internal organs outside their bodies, to mention but a few malformations. In hospitals across Iraq the mothers are no longer asking: 'Doctor, is it a boy or girl?' but rather: 'Doctor, is it normal?'[18] Several researchers outside Iraq, as well as United States (U.S.) veterans' organizations concur.[19] Afghanistan is another country with a relatively similar affliction. DU has been used there, and a doctor reported that observed '[m]alformations include neural tube defects and malformation of limbs; for example, the head is smaller than normal, or the head is larger than normal, or there is a big mass on the back of the baby.'[20] This nightmarish forewarning could happen in Lebanon.

During the July 2006 Israeli aggression on Lebanon, Doug Rokke, previous Director of the U.S. Army DU project, stated that the US delivered 'at least 100 Guided Bomb Unit 28 bunker busters bombs containing DU warheads . . . to Israel for use against targets in Lebanon. (. . .) Israeli tank gunners are also using DU tank rounds as photographs verify.'[21] The effects of DU on foetuses are ghastly, as foetuses are quite vulnerable to radiation damage: cells are quickly dividing and the limbs are growing. Hence, radiation and noxious chemicals damage foetal development seriously. As stated by Domingo, 'embryo/fetal toxicity including teratogenicity and reduced growth of the offspring have been observed following uranium exposure at different gestation periods.'[22] Once born, the child would suffer handicaps that are incompatible with life. This unfortunately highly plausible scenario, as evidenced from what happened in Iraq and Afghanistan, to mention only two countries, places a number of potential foetuses at deplorable threat of disastrous harm. The birth of these potential beings qualifies as a wrong. Hence, one cannot but wonder whether this does not constitute 'valid justifiable reasons for interrupting a pregnancy.' Everyone recalls the birth defects resulting from the use of the drug Thalidomide. Although many would argue that ensuing foetal deformities were not 'incompatible with life,' litigations and cries for justice and legal amendments followed. Hiroshima's 'mushroom cloud' is another famous story that has not managed to make itself forgotten. Many people have been affected by radioactive outcomes. Pregnant women gave birth to children with terrible defects and the world is still outraged. Gallagher recounts the story of a mother and daughter whose lives have been severely affected:

> [W]hile she was carrying her daughter in the womb, she was exposed to test fallout that caused nausea, burns, and blisters on her skin and led to the loss of her teeth, hair, fingernails, and toenails. Her daughter was subsequently delivered prematurely, suffering from cancer, and weighing little more than three pounds. At the age of six months her cancer was treated with crude and unlocalized radiation that deformed her heart, lungs, breasts and spine. As Diana Lee Woosley aged she suffered from constant vomiting and congestive

[17] J.-H. Westen. 2006. Pope: Abortions are 'Never Justifiable' Even in Cases of Fetal Abnormality. *LifeSiteNews.com* 28 September. Available at: http://www.lifesitenews.com/ldn/2006/sep/06092807.html [Accessed 26 Aug 2010].

[18] D. Westerman. 2006. Depleted Uranium – Far Worse Than 9/11. *GlobalResearch.ca* 3 May. Available at: http://www.globalresearch.ca/index.php?context=va&aid=2374 [Accessed 30 May 2009].

[19] L. Johnson. 2002. Iraqi Cancers, Birth Defects blamed on U.S. depleted Uranium. *Seattle Post-Intelligencer* 20 November. Available at: http://www.seattlepi.com/national/95178_du12.shtml [Accessed 26 Aug 2010].

[20] D. Azami. 2008. Afghan 'health link' to Uranium. *BBC World Service* 30 April. Available at: http://news.bbc.co.uk/go/pr/fr/-/2/hi/science/nature/7373946.stm [Accessed 26 Aug 2010].

[21] D. Rokke. 2006. Depleted Uranium Again, But Now in Lebanon. *A Citizen of Mosul* 28 July. Available at: http://moslawi.blogspot.com/2006/07/depleted-uranium-again-but-now-in.html [Accessed 26 Aug 2010].

[22] J.L. Domingo. Reproductive and Developmental Toxicity and Natural Depleted Uranium: A Review. *Reprod Toxicol* 2002; 15: 603–609: 603.

> heart failure and underwent traumatic surgical procedures to correct her spinal deformity. Her face, we learn, is swollen from large doses of prednisone, which she must take to combat the diseases that exploit her weakened immune system-a treatment that has itself caused diabetes. Beyond this suffering of their bodies, however, the women have also suffered psychologically.[23]

This resulting unnatural lottery, the torment and pain, psychological and physical (as well as financial) that Diane Lee Woosley (and her mother) underwent cannot be overlooked.

Suggested policy change

Recent scenarios have revealed that the Lebanese policy on abortion is not practically feasible, does not have the best interest of the patient in mind (whether the patient is the unborn child, the future child or the mother) and is being often ignored and contravened by patients, doctors and committees alike. At this point, one cannot but wonder whether in the face of such possibilities, and in the face of actual breaches of the policy on abortion emanating from doctors' conscientious objections and based on the wishes of autonomous and informed parents, efforts should be made to amend it for the benefit of the foetus and the parents. Thus, an Article can be added to the effect that *if it were medically revealed that there is substantial risk that the born child will suffer from severe physical abnormalities that will cause it to be seriously handicapped; it is morally acceptable to abort it*. To put it more elaborately, we are arguing that, as it is, the Lebanese Law is mistaken in judging all abortions immoral (except those that are done to save the life of the mother). We want to argue that abortions carried out because of foetal congenital malformations incompatible with life, are justified in the interest of the foetus and the child. We believe that it is better for the child not to be born to begin with, than to be born with a defect that it incompatible with 'normal' life.

QUANTIFICATION OF RISK?

A foetus whose mother is exposed to varicella infection during the first 20 weeks of gestation is at a 2% risk of the congenital varicella syndrome, which is characterized by skin scarring, limb hypoplasia, chorioretinitis and microcephaly. On the other hand, *in utero* exposure to rubella during the first trimester has up to a 25% chance of having one or more birth defects including eye defects, hearing loss, heart defects and mental retardation. The question that comes to mind is: what constitutes 'substantial risk'? This must be clearly elucidated. To that end, a committee consisting of physicians (obstetrics, neonatology, paediatrics, psychology and general practice) and bioethicists should be formed to set necessary and sufficient criteria. Furthermore, what is it that constitutes a 'serious handicap'? This might be even more difficult to define. For example, a condition that is incompatible with life, such as anencephaly, is quite different from a condition that is incompatible with a *normal* life, like cystic fibrosis. It might not be easy to draw the line between what should be considered a malformation or a condition that is compatible with a 'normal' life and what constitute a serious handicap that makes life not worth living. However, the difference between a condition like Down syndrome, where the severity of health problems including the degree of mental retardation vary greatly among affected individuals and Tay-Sachs disease, a uniformly fatal disease, cannot be overemphasized. Should these be limited to conditions that are associated with mental disabilities, like major neurological or chromosomal abnormalities, or can this be extrapolated to include diseases that are associated with shortened life expectancy, 'very painful' life or serious disfigurement?[24] Certain countries like the United Kingdom (UK) have grappled with this issue especially after the *Jepson v. Chief Constable of West Mercia Constabulary*[25] case in 2003 (against two physicians who performed an abortion on a foetus of over 24 weeks, for cleft palate, in 2001). The UK explicitly rejects a 'list' approach. It is left to the discretion of physicians to decide whether a substantial risk exists whether the newborn would suffer from abnormalities (physical or mental) that will lead him to be seriously handicapped.

Thalassaemia describes a group of inherited disorders that cause varying degrees of anaemia which can range from insignificant to life threatening. Although the prognosis for individuals with thalassaemia has improved drastically over the past several years, the life expectancy and quality of life of affected individuals is not yet comparable with that of the general population. So, would thalassaemia qualify as a condition that is not compatible with 'normal' life? Even in Iran – a conservative

[23] B.C. Taylor. Nuclear Pictures and Metapictures. *Am Literary Hist* 1997; 9: 567–597: 583.

[24] One might even argue that there may be no line to draw, to begin with, as a great number of disability theories have come to show that disability is related to context. For example, research from the UK and the USA has revealed a strong link between disability and low income. Similar results seem to appear in Australia and the Netherlands; B. Bradbury, K. Norris & D. Abello. Socio-Economic Disadvantage and the Prevalence of Disability. In *SPRC Reports 1/01*. Sydney, Australia: Social Policy Research Centre, University of New South Wales. Available at: http://www.sprc.unsw.edu.au/media/File/Report1_01_SocioEconomic_Disadvantage.pdf [Accessed 26 Aug 2010].

[25] [2003] EWHC 3318.

Muslim country – following extensive public debate, the abortion law was amended to permit early selective termination of foetuses with thalassaemia.[26] However, this agreement is far from being universal. A more difficult example is a foetus with cleft lip with or without cleft palate. Some might argue that a severe bilateral cleft lip and palate which entails several surgical repairs that can carry potential risks and that may eventually result in facial asymmetry, deformity of the nose, speech problems, malalignment of teeth and even low-self esteem is a condition where TOP should be offered as an option to the parents. Meanwhile, pro-life activists lobby against allowing TOP in these cases because they claim that this is not a serious enough disability to justify abortion. Hence, a committee should also be formed to set the requisite criteria. Some factors, including the prospect of effective treatment (either *in utero* or after birth),[27] the likely potentials for self-awareness and ability to communicate with others and the suffering that the born child might undergo or that the people caring for the child might experience, must also be taken into considerations by the committee. Since parents can know if their child will be born with severe physical deformities, they should also be given the option of TOP should this deformity prove to be incompatible with life or 'normal' life.

Nonetheless, if one were to argue that a list should be set that specifies which conditions are 'severe' and which are not, one cannot help but wonder whether conditions that are not listed will be considered 'insignificant' and if so, to whom? Will insignificance and severity become subjective? For a mother who has suffered all her life from a cleft lip and palate, having a child with this deformity is not trivial and will strongly impact the life of the child. Some, like Shaw, argue that in a world of deficient resources, expenses related to disabilities can be minimized if all diagnoses of foetal impairment are followed by TOP.[28] Shaw might be pushing it too far. The dignity of life is not something to be brushed aside. Indeed it is precisely because we believe that human life is precious and human beings important that we are arguing for a life, free from agony and offense. Thus, to say that impaired foetuses are to be aborted in order to minimize expenses seem to us to devalue life.

Consider a child with a large meningomyelocele. Many years ago, and in several underdeveloped countries, this child might have died 'naturally'. Today, with the advancement of medical technology, he leads a wretched life: paralyzed, with no bowel or bladder control, with respiratory problems and hydrocephalus. Although the physician's calling is to save lives whenever possible and to ease suffering, one cannot deny that the responsibilities of the physician are becoming more complex with the advances in medical technology. Should he/she prolong every life possible regardless of the quality of that life? Today, most pregnant women go through a series of tests in order to find out whether their foetus has birth defects. Some couples get screened even before attempting pregnancy to see whether they are carriers of certain genetic disorders. In certain countries, intrauterine treatments are often offered. Yet, these tests and treatments are often done with a plethora of ethical decisions: there are risks involved as well as sporadic inaccuracies which have serious repercussions. Contemplate the case of a foetus with hydrocephalus treated *in utero*. Once born, the baby suffers from grave abnormalities such as cortical blindness, seizures, and retardation. It is cases such as these that led to a moratorium on foetal surgery. The right to life does not trump the quality of life (QoL) and as such, we have a moral obligation to the not-yet-born. The question remains about the limits of this obligation. Lorber, a paediatrician who treats similar cases, questions whether severely handicapped newborns should be saved. In an article published in 1971, he argued that severe cases should not be treated since most had mental and/or physical defects incompatible with life.[29] Physicians in the UK were debating whether all premature neonates (around 24 weeks or less and weighing less than 1 lb) should be resuscitated. Britain's renowned medical ethics expert, Baroness Warnock argues that one should set a limit, below which neonates would not be resuscitated. The reason behind this is that some children may not survive or may end up with severe disabilities.[30] This brings us to another question: is it better not to be born to begin with than to be born and left to die in order not to suffer afterwards?[31] Clearly, the option of living in suffering is one we are trying to avoid from the beginning. The first idea that comes to the mind of the reader upon reading this question is neonaticide. Are the authors advocating the killing of neonates? Here, it is enough to say that foeticide, neonaticide and infanticide, like any form of 'killing', are intuitively morally abhorrent. But thinking of the depleted uranium scenario and of a

[26] A. Christianson, A. Streetly & A. Darr. Lessons from Thalassaemia Screening in Iran. *BMJ* 2004; 329: 1115–1117.

[27] Foetuses with certain congenital malformations can sometimes be treated by foetal surgery. However, the procedure is still experimental. A moratorium has been called until better understanding of the procedure, and more experiments, are done.

[28] M.W. Shaw. Presidential Address: To Be or Not To Be, That is the Question. *Am J Hum Genet* 1984; 36: 1–9.

[29] J. Lorber. Results of Treatment of Myelomeningocele: An analysis of 524 Unselected Cases, With Special Reference to Possible Selection for Treatment. *Dev Med Child Neurol* 1971: 13: 279–303.

[30] S. Womack. 2005. Babies 'should not be saved' at 24 weeks. *The Daily Telegraph* 6 June. Available at: http://www.telegraph.co.uk/news/uknews/1491464/Babies-should-not-be-saved-at-24-weeks.html. [Accessed 26 Aug 2010].

[31] This is an unavoidable question worth pursuing, but which falls outside the scope of this article.

paradigm case like that of Baby Andrew, who agonized every time he drew a breath,[32] we are forced to entertain the thought that at times it is not morally unthinkable; it becomes a form of respect for human life. Critics can also maintain that once a principle is established, according to which it is morally justifiable to 'kill' on the grounds of suffering, then logically it extends to all forms of suffering and hence a call for a policy allowing euthanasia will soon be an issue. This is a vast topic which cannot be discussed in this article; however, it deserves much attention from bioethicist and policy makers.

Some might even argue that inherent in the new policy is an insinuation or an affirmation that life with disability is not worthwhile. The 'aborting Beethoven' argument is often invoked, although this has been attacked by Harris as a fallacy, since opting to terminate the birth of the foetus with syphilis does not mean that the world is better off without Beethoven.[33] Bioethicist Adrienne Asch voiced her concerns about a society that views genetic disabilities as reasons to terminate a pregnancy. According to Asch, mothers should think carefully before thinking of aborting their foetuses who are less-than-normal.[34] Still, a mother who decides to terminate a pregnancy on the grounds of severe foetal deformities is not making a statement (social or political) about abnormality or disability. Rather, she is making a choice about her personal life and beliefs. This is an argument from autonomy which is not one we are currently concerned with since it is not concerned with the welfare of the foetus. Thus, we will not expand it further. Parents who have children born with severe defects are already burdened psychologically and financially. This affects the ability of parents to care for other children and/or to undertake household tasks or jobs outside the households. In Lebanon, there are hardly any support systems available. The prospect of more potential victims due to DU is nightmarish. The Lebanese government offers very few options for financial assistance. What if the child needs multiple surgeries and the parents cannot afford them? What if he/she needs a series of treatments? As it is, health care expenditure is too high and the public is outraged. Unfortunately, such options often go to those who either can afford it themselves or have special ties with VIPs. Indeed, whatever endowments a person might happen to obtain as a result of the 'natural lottery', to borrow a phrase from Rawls, or suffer as a result of an unnatural lottery, they can live and give to everyday society, and examples abound. Every person is a member of the moral community. However, our argument is specifically about foetuses who suffer physical abnormalities that are incompatible with life. These persons-to-be will suffer an exceedingly low QoL and will be tormented. Modern medicine spends time and effort to cure severely ill suffering children. This involves pain and agony (and finances) for all stakeholders. If this can be spared, is there no moral obligation to do so?

The potential of increasingly uncovering new genetic markers has generated a heated debated centering on the idea that foetuses whose genes are not perfect will be aborted. A study by Breslau on a sample of mothers in Cleveland, Ohio revealed that 'the majority of mothers of congenitally disabled children, like the majority of the general public, do not defend the right to life of defective fetuses.'[35]

More generally does allowing TOP on the grounds of severe physical abnormalities incompatible with life devalue life? What is life to begin with and how will it be devalued if the suggested TOP law were ratified? Is life merely breathing and existing biologically? If this were the case, what are the implications on the physician-patient relationship? Also, let us look at this issue from an existential perspective: What differentiates a person from a snail or a rabbit? This is not to say that humans are more valuable than their fellow non-humans; nor is it to say that cognizant persons who are not dependent on life sustaining machines are more valuable than persons in a persistent vegetated state (PVS).[36] It is simply to say that when given the option of starting an existence, this person-to-be has the right to a minimum that allows him/her to lead a life with a relatively good QoL. The Nuffield Council on Bioethics defines QoL as 'a person's emotional, social and physical well-being, their intellectual capability, and their ability to perform the ordinary tasks of living with a community.'[37] Needless to say that the question of who determines what QoL is remains well-founded. Furthermore, QoL is non-measurable. Are there guidelines or criteria like pain criteria that one can scientifically follow to decide what constitutes low and high QoL? A foetus diagnosed with AIDS, Tay-Sachs or myelomeningocele is agony and misery in the making. He/she will not be able to fulfill a rational plan of life, nor a conception of the good. His/her autonomy will be reduced; he/she will be dependent on others, in pain and awaiting a slow death. Is it right

[32] P. Singer. 1999. *Practical Ethics.* New York, NY: Cambridge University Press.

[33] J. Harris. One Principle and Three Fallacies of Disability Studies. *J Med Ethics* 2001; 27: 383–387.

[34] A. Asch. 1995. Can Aborting 'imperfect children' be Immoral? In *Ethical Issues in Modern Medicine*. J. Arras & B. Steinbock, eds. Mountain View, CA: Mayfield Publishing Company: 385–392.

[35] N. Breslau. Abortion of Defective Fetuses: Attitudes of Mothers of Congenitally Impaired Children. *J Marriage Fam* 1987; 49: 839–845: 844.

[36] This falls outside the scope of this article.

[37] Nuffield Council on Bioethics. 2006. *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues.* London, UK: Nuffield Council on Bioethics. Available at: http://www.nuffieldbioethics.org/fileLibrary/pdf/CCD_web_version_22_June_07_(updated).pdf [Accessed 26 Aug 2010].

to bring him/her to life to watch him/her slowly wither away in pain and humiliation?

CONCLUSION

Today, physicians in Lebanon are confronted with the burden placed on them under the law to refuse TOPs or, when performing them, to forge records or deny having done them. Rather than acting stealthily, many would prefer specific guidelines to guide them in making decisions about actions and counselling in cases of severe foetal deformities. If we are to start thinking of Lebanon as a country where patients are not passive spectators anymore, where the culture of rights, duties, obligations and medical ethics is starting to take shape, then we have no option but to critically reflect on the idea of responsible reproduction and allow women the legal right to make enlightened decisions.

Baby Z. has major congenital malformations. No one knows how long he will live. To his poor, illiterate and religious family, he is a gift from God. What will he be to himself? Time will tell.

Biography

Thalia Arawi is the Clinical Bioethicist and the Founding Director of the Salim El-Hoss Bioethics and Professionalism Program at the American University of Beirut Faculty of Medicine. She is also member of the American Society of Bioethics, the Canadian Society of Bioethics, the Provincial Health Ethics Network and other bioethics societies. Her research interests are mainly in the areas of animal rights and biomedical ethics. **Anwar H. Nassar** received a degree in Medicine from the American University of Beirut with a specialty in Obstetrics and Gynaecology. He pursued further studies at the University of Miami, before the American University of Beirut Medical Center. He is currently an Associate Professor in the Department of Obstetrics and Gynaecology. Dr. Nassar has published several papers in international peer-reviewed journal and was selected as a member of ALPHA OMEGA ALPHA (AΩA) honour medical society.