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Prenatal screening in Jewish law

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Author's abstract

Although prenatal screening is routinely undertaken as part of a woman's antenatal care, the ethics surrounding it are complex. In this paper, the author examines the Jewish position on the permissibility of several tests, including those for Down's syndrome and Tay-Sachs disease, the latter being especially common in the Jewish community. Clearly, the status of the tests depends on whether termination of affected pregnancies is allowed, and contemporary rabbinical authorities are themselves in dispute as to the permissibility of terminating affected pregnancies. The nature of these arguments is examined and the author concludes that there are grounds on which the full range of prenatal screening is permitted in Jewish law.

Prenatal testing is now a standard part of a woman's antenatal care, whether she is under the care of her general practitioner or a hospital obstetric department. A wide number of conditions can now be diagnosed antenatally, including congenital intra-uterine infections such as rubella, neural tube defects, Tay-Sachs disease and Down's syndrome. Although a large number of conditions may be detected, it is usual practice only to test for certain of the commoner conditions, namely congenital syphilis, rhesus status, neural tube defects, maternal rubella status and Down's syndrome in those women at increased risk.

Although it is considered good medical practice to offer antenatal testing as a routine, the options open to the medical profession and the family once an abnormality has been detected are few. Why then is testing performed? It seems that there are three reasons. Firstly, the test may prepare prospective parents for the arrival of a child who will have special difficulties, and enable them to make the necessary preparations and adjustments. Secondly, diagnosis of an abnormality may alert the medical team to a condition which is curable, and thus allow a happy outcome. For example, once the problem of rhesus incompatibility has been detected through screening, it is easily alleviated and future difficulties are prevented. Finally, diagnosis of a fetal abnormality may allow the pregnancy to be terminated under the 1967 Abortion Act. In a recent survey of the British public, 67 per cent of those questioned were in favour of allowing a termination at more than twenty weeks of pregnancy if the physical health of the child was shown to be in danger (1); in 1986 approximately 2000 terminations were carried out because of a known or suspected fetal abnormality (2).

Terminations because of fetal abnormality are widely accepted in society but what could be their moral justification? A full analysis of the status of the fetus is beyond our present scope, but clearly any legal system that permits abortion must consider the fetus to have weaker rights or claims to our protection than do other human beings. Indeed, in those countries where abortion on demand is permitted, the fetus clearly has no rights of its own. In the United Kingdom, the law admits of relative rights of the fetus, in so far as there must be a reason for the termination to be performed. Such a system would concede that a fetus has rights, but that those rights are not sufficient to protect its life under some circumstances. Where the life of the mother is at risk the overriding of fetal rights is understandable. But the Abortion Act of 1967 also permits terminations to be carried out because of '... a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped' (3). The justification for this is not clear. For the fetus under consideration, the 'choice' is not whether to be born handicapped or healthy, but rather whether to be born handicapped or never to exist (4). Under these circumstances, it is difficult to understand how it can be in the interests of the fetus to be aborted, unless it can be argued that a handicapped life is worse than non-existence. Certainly we may imagine that there are indeed some conditions that are so horrendous that we would consider non-existence preferable, but this surely would not apply to all of the conditions for which abortions are presently carried out. We must therefore look elsewhere for a justification of abortion because of future handicap to the child. Perhaps the child will take up too much parental time and prevent them from adequately caring for their other children; perhaps the

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financial burden placed on society in terms of nursing and caring is too great to bear. Whatever the justification, it is clear that an individual must be able to defend rationally the decisions he or she takes concerning the temination of handicapped fetuses, and all too often such a defence is lacking.

The Jewish position on the permissibility of abortion is by now well known and widely documented (5). Judaism stands in strong opposition to a liberal abortion policy, and views the fetus as having a strong claim to protection by society. This claim however, must be distinguished from that of the Catholic Church, which does not permit abortion under any circumstances, even in a case where continuation of the pregnancy will lead to the death of both mother and infant, for '... to save the life of the mother is a most noble end, but the direct killing of the child as a means to this end is not licit' (6). In Judaism, the life of the mother is given the highest priority, and if there is any threat to her well-being, an abortion may be carried out, after careful consultation with medical and rabbinical experts.

What then is the Jewish view regarding prenatal testing? If Jewish law known as the *halakha* (literally 'the way') views the termination of pregnancy as a serious violation of both Jewish and non-Jewish natural law (7), should a pregnant woman have prenatal tests to ascertain the health of her child? Clearly, if a mother wanted to know in advance of the birth that her child was healthy, but would not have an abortion in the light of any handicap which may be uncovered, the prenatal tests would be permitted. In a recent survey of geneticists in several countries, 83 per cent would perform prenatal diagnosis for parents who oppose abortion but who request such a service (8). However, if the mother might act on the results, the *halakha* is much more complex.

Jewish law is not static, despite the belief that the *Torah*, the Five Books of Moses, were revealed at Sinai as the source of that law. Rather, there is '... an insistence on the human share and responsibility in the interpretation and the administration of the revealed Word of God' (9). As will become clear, the grounds for termination of pregnancy depend to a great extent on exactly which legal authority is asked (10).

The basis of the prohibition

Intentional abortion is not mentioned in the Bible, but there is a reference to a case of accidental abortion:

'When men fight and one of them pushes a pregnant woman and a miscarriage results ... the one responsible shall be fined ... but if other misfortune results, the penalty shall be life for life' (11).

That feticide is not considered murder is learnt out from the verse 'He that smites a man so that he dies shall be put to death' (12). The Talmud, a commentary on the *Torah* codified in the year 500 CE, comments that the word 'man' teaches that murder of a fetus does not fall under this prohibition. This exegesis is usually considered the source for the prohibition as it applies to Jews. However, there also exists a prohibition for gentiles to destroy fetal life based on the reading of the verse 'who sheddeth the blood of man *within* man, shall his blood be shed', rather than the usual reading 'who sheddeth the blood of man, by man [ie through a court] shall his blood be shed' (13). The Talmud questions who this 'man within man' could be, and deduces that it refers to a fetus within the womb (14). Since this verse is the source of the Noachide laws, feticide is prohibited to gentiles as well as to Jews.

The *Mishna*, a collection of laws codified in the year 200 CE and on which the commentary of the Talmud is based, develops the laws of feticide:

'If a woman is having difficulty in giving birth [such that her life is in danger] one cuts up the fetus within her ... because her life takes precedence over that of the fetus. But if the greater part was already born, one may not touch it, for one may not set aside one person's life for the sake of another' (15).

Two main reasons are given for the law permitting this embryotomy. Either the unborn fetus is not considered a full person with all the rights that are usually associated with personhood, or the fetus has the status of an aggressor 'pursuing the life of its mother'; Jewish law demands the pursued to exercise the right of self-defence and stop the attacker by whatever means are necessary. In his codification, Maimonides favours the second explanation (16), as does the authoritative fifteenth century code of Jewish law, the *Shulchan Aruch* (17).

It must be emphasised that just as an abortion may be carried out if the physical health of the mother is under severe threat, so too a termination may be carried out under those circumstances in which the mental health of the mother is at risk. With certain notable exceptions (18), most *halakhic* authorities do consider psychiatric morbidity as a danger to life and may therefore permit termination of pregnancy should the mother's mental health be threatened (19). The Chief Rabbi of the United Kingdom, Lord Jacobovits, has summed up the Jewish view as: '... on the one hand, a refusal to grant full human inviolability to the unborn child from conception, and, on the other hand, clear recognition that potentiality for life must not be compromised except for the most substantial medical reasons' (20). It is to the precise nature of these medical reasons that we may now turn.

Rubella

Congenital rubella syndrome, first recognised in 1942, is a result of maternal infection with the rubella virus and is characterised by the triad of cataracts, heart defects and nerve or perception defects. Neurological abnormalities include cerebral palsy, epilepsy, mental retardation and autism. Infection in the first two months of pregnancy is more likely to produce

multiple defects, and at least a quarter of children born of mothers infected with rubella early in pregnancy have defects (21,22).

Among the modern *halakhic* authorities who ruled on the permissibility of abortion following maternal infection with rubella was Rabbi Y Weinberg (d 1966). In a long responsa written to a doctor in London, he wrote that termination of a pregnancy within the first 40 days was permitted since the embryo is 'nothing but an [insignificant] collection of cells' *(maya be' almah)* (23,24). Rabbi Weinberg also quoted the responsa of Rabbi Emden, who lived in Germany at the end of the eighteenth century, and who permitted terminations if the mother would suffer great emotional stress; these terminations were permitted even after the first forty days (25). However, Rabbi Weinberg emphasised that his entire answer is based on those sources which permit abortion because the fetus does not yet have all those rights associated with persons. If however, one accepts the opinion of Maimonides, the fetus with congenital rubella is not pursuing the mother's life, and one could not permit the pregnancy to be terminated. However, Rabbi Weinberg concluded that the majority opinion considered that the fetus was not in possession of full rights since it was not a full person, and therefore abortion in the case of congenital rubella was permitted. However, one must add that even on the understanding of Maimonides, the mother's mental health may be 'pursued' if the fetus is disabled, and on these grounds alone termination may be permitted. Rabbi Waldenberg, a Judge of the Jerusalem Rabbinical Court, also ruled that termination was permitted where there exists the possibility of serious disability and allowed this to take place until the end of the first trimester, and before quickening (26).

Rabbi Unterman, who served as Israel's Chief Rabbi some twenty years ago, ruled against the termination of pregnancy in cases of rubella infection. He wrote that such an infection did not come under the category of life-threatening events as far as the mother was concerned, and was suspicious of the true motives of parents requesting such a termination; the prohibition against taking life is not suspended to enable parents to have an easier life than they would otherwise have done had a severely disabled child been born (27). Rabbi Weinberg published an addendum to his responsa quoted above, in which he wrote that since Rabbi Unterman had published his opposition to terminations for congenital rubella, it was necessary to 'seek advice from the leading *halakhic* authorities' when considering what action to take. Rabbi Moshe Feinstein, who until his death in 1986 was the leading rabbinical authority in the United States, ruled that there can be no reason to abort a fetus, even within the first forty days of pregnancy (28).

To conclude, whilst some authorities would allow abortion in the case of congenital rubella infection, there are many who do not, and the doctor must carefully consider the various rulings before recommending antenatal screening for a woman who may have been infected with rubella whilst pregnant. In England and Wales there are about 140 therapeutic abortions a year because of rubella infection (29). Many hope that the new rubella vaccination programme will eliminate congenital rubella and with it the need to terminate affected pregnancies.

Down's syndrome

Down's syndrome is the most common serious chromosomal abnormality, and the one for which antenatal screening is most commonly undertaken (30). The most common abnormality is that three copies of chromosome 21 are present. All types of Down's syndrome have the same clinical features, the hallmark of which is mild to severe mental retardation. There is also general growth retardation and a lack of muscle tone. Between 22 and 31 per cent of affected children die within the first year of life, and after the age of ten years the mortality rate is about seven times higher than that of the general population (31,32). The risk of giving birth to a Down's syndrome infant varies with maternal age; various studies have reported the rate at between 1.82 and 0.18 per 1000 live births at a maternal age of less than 20 years, whilst at a maternal age of 40-44 years the rate increases to between 18.7 and 8.6 per 1000 live births (30). There is an increased risk of recurrence if a previous child has been born with Down's syndrome. Screening involves amniocentesis performed at 15 to 16 weeks' gestation and tests on amniotic fluid usually yield a result in seven to ten days.

The question of the permissibility of both amniocentesis and consequent termination if Down's syndrome was discovered, has been addressed by Rabbi Waldenburg in a responsa written in 1978. He allowed amniocentesis to be performed, but cautioned against termination:

'One should not deduce from this [permission to undergo amniocentesis] a general principle of leniency ... but once the results of the test are known the doctor should send the mother to an expert rabbinical authority together with the results, and the Rabbi should assess the mental state of the couple, and decide on the permissibility of termination' (33).

In another responsa on the same question, he advised against having amniocentesis, unless the couple had previously given birth to an infant with Down's syndrome, or if the mother was in a high-risk age group. In such cases, if the mother was most anxious and insisted on having the test, permission could be granted. Rabbi Weinberg based part of his opinion on the fact that although the risk of giving birth to an infant with Down's syndrome may be as high as 2 per cent in those over 45 years, the overwhelming majority of older women would produce healthy babies. He also noted the recognised risk to the fetus if the procedure is carried out (34). It is interesting to note that Rabbi

Waldenberg also insisted on the agreement of the father of the child before allowing a termination. Given that in England the test for amniocentesis is only offered to high-risk pregnancies, one may conclude that based on the opinion of Rabbi Waldenberg, screening for Down's syndrome would be permitted.

Neural tube defects

Neural tube defects are one of the most common congenital malformations. Their cause is not presently known, and the only proven method of prevention is antenatal screening and diagnosis, followed by termination of affected pregnancies (35). Eighty per cent of cases of neural tube defects and over ninety per cent of those of anencephaly can be detected by an increased maternal serum alpha-fetoprotein (AFP) concentration at 16-18 weeks' gestation (36). If a high concentration is detected, ultrasound scanning is undertaken (to ensure that the result is not due to a reason unconnected with neural tube defects, such as multiple pregnancy or miscalculated gestational age) and amniocentesis may also be offered.

The *halakhic* permissibility of the routine AFP test has not been discussed directly. However, the Talmud does discuss the birth of an anencephalic child, and concludes that the mother of such a child does not become ritually impure, as she would do following the birth of a normal child (37). The status of the anencephalic may be deduced from Maimonides's codification of the Talmudic law, in which he wrote that:

'If a woman gave birth to a second child following the birth of a child which did not render her impure, this second child is considered her firstborn and requires redeeming [as do all firstborn] (38).

At least one contemporary *halakhic* authority has deduced from this law that the anencephalic infant does not have the status of a *nefesh*, a being with a soul, and as such does not have a claim to our protection. The abortion of such a child therefore carries no prohibition whatsoever (39). This being the case, it would seem reasonable to conclude that the antenatal test carried out to detect such cases would be permitted, although this author is not aware of any responsa to this effect (40). However, the test also detects open spina bifida, and clearly infants affected with this are most certainly not given the same status as anencephalics. In the absence of clear rabbinical guidance it is therefore difficult to assess the *halakhic* advisability of the AFP screen.

Tay-Sachs

Although Tay-Sachs disease is rare and is not usually screened for, its prevalence among the Ashkenazi Jewish population means the antenatal screening test for it is of special interest in Jewish medical ethics. Tay-Sachs is a lysosomal enzyme disorder involving the activity of a specific enzyme. Deficient activity of this enzyme, hexosaminidase-A2, results in an accumulation of the lipid GM2 ganglioside. Children with Tay-Sachs disease develop normally during the first few months of life, but by six months progressive neurological degeneration occurs, head control is lost, and convulsions may set in. By the age of two blindness and head enlargement are manifest, and the child requires constant nursing. There is no known cure for the disease, and death occurs before the age of five, usually from cachexia and aspiration pneumonia (41). The Tay-Sachs carrier frequency among Ashkenazi Jews is about 1 in 30, and among other groups is about 1 in 380. In Britain most of the affected families are non-Jewish, while in New York most are Jewish (42). Screening of the teenage Jewish population may be carried out so that carriers of the defective gene are identified early on in their reproductive years, or alternatively prospective partners may be tested. The test may also be carried out antenatally on a sample of amniotic fluid.

There are two aspects of the screening programme for Tay-Sachs disease that need to be examined. The first is screening for carriers among the general Jewish population. Rabbi Moshe Feinstein was of the opinion that:

'... it is advisable for one preparing to be married to have himself tested. It is also proper to advertise that such a test is available. It is clear ... that absolute secrecy must be maintained to prevent anyone from learning the result of such a test performed on another' (43).

Rabbi Feinstein was worried about the psychological stress which the test results might place on an adolescent, and therefore encouraged testing only those who were thinking of starting a family.

With regard to antenatal diagnosis, the noted American writer and *halakhic* authority Rabbi JD Bleich wrote that:

'The fear that a child may be born physically malformed or mentally deficient does not in itself justify recourse to abortion... . Since the sole available medical remedy following diagnosis of severe genetic defect is abortion of the fetus, which is not sanctioned by *halakha* in such instances, amniocentesis under these conditions does not serve as an aid in the treatment of the patient and is not *halakhically* permissible' (44).

A similar opinion is expressed by Rabbi Feinstein who forbade antenatal testing for, and termination of, a fetus with Tay-Sachs disease (45). His lengthy reasoning is highly critical of the lenient position of Rabbi Waldenberg, who permitted termination of a fetus with Tay-Sachs disease up to the seventh month of pregnancy because 'the defect, the anguish, the shame, the physical and mental suffering of the parents ... are inestimable' (46). This lenient opinion is based

in part on a responsa of Rabbi Joseph Trani, who permitted abortion where there is no danger to the mother's life (47). Rabbi Feinstein opines that the responsa is a forgery, and that it was falsely ascribed to Rabbi Trani. Rabbi Feinstein also believed that a vital *Tosafot* (a gloss on the Talmud written in the middle ages) contains a scribal error, and he criticised a lenient ruling of Rabbi Jacob Emden. Emden, who lived in the eighteenth century, allowed the abortion of a fetus conceived as a result of a union forbidden in Jewish law, since such a child (known as a *mamzer*) is subject to many restrictions. In reaching his conclusions, Emden wrote that '... there are grounds to permit [termination] ... even when the life of the mother is not threatened, in order to prevent her from great psychological distress' (48). This ruling was understood by Rabbi Waldenberg on the one hand, as a precedent on the basis of which to permit termination in cases of great maternal suffering. Rabbi Feinstein on the other hand took Emden's phrase 'there are grounds to permit [termination]' as implying that there are many *more* grounds for not doing so! This dispute between Rabbi Feinstein and Rabbi Waldenberg, the two leading contemporary *halakhic* authorities, will remain unresolved following the death of Rabbi Feinstein. Scholars have sided with one opinion or the other; rabbinic scholars such as Rabbi Bleich point out that Rabbi Waldenberg's ruling is contrary to the vast majority of rabbinic opinion (49), whilst university academics such as David Sinclair from the Hebrew University in Jerusalem notes that it is: '... unusual for a *halakhic* dispute to be resolved by declaring inconvenient sources to be forgeries, and the employment of such tactics raises doubts as to the legal integrity of the argument as a whole' (50).

In sum, there are grounds on which to permit antenatal screening for Tay-Sachs, and all opinions permit, if not actively encourage, screening programmes for the detection of carriers of the defective gene (51).

The prevention of congenital abnormalities is a goal all would like to see achieved. The question that must be addressed is to what extent this goal may be attained at the expense of other values in Jewish law. Whilst attempting to provide an overview of the contemporary *halakhic* positions regarding antenatal testing, it must not be forgotten that each case is unique, and therefore it is most dangerous to provide general rules or guidelines. Thus, the need for a close working relationship between the expert medical practitioner and competent rabbinic authorities is of crucial importance. This, coupled with care and sensitivity, can help to ease the anguish of those families confronting these difficult and often painful ethical decisions.

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(12) Exodus 21:12.
(13) Genesis 9:6.
(14) *Sanhedrin* 57b.
(15) *Ohelot* 7:6.
(16) *Hilkhot Rozeah* 1:9.
(17) *Shulchan Aruch Choshen Mishpat* 452:2.
(18) Rabbi Unterman. *Hatorah veHamedinah* IV, 27.
(19) Waldenberg Rabbi, E. *Tziz eliezer* 9 :51–53; Feinstein Rabbi, M. *Iggeret moshe; even haezer* 1:65; Weiss Rabbi, I J. *Minhat yizhak* 1:115.
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(25) *Sheelot uteshuvot yaavetz* :43.
(26) *Sheelot uteshuvot tziz eliezer* 9:51–53.
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(47) *Sheelot uteshuvot maharit* 97 and 99.
(48) *Sheelot yaavetz* 1:43.
(49) Bleich Rabbi, JD. *Contemporary halakhic problems.* New York: Ktav Publishing House, 1977:109–115.
(50) Sinclair DB. *Tradition and the biological revolution.* Edinburgh: Edinburgh University Press 1989:96. Sinclair includes a careful analysis of the positions of Waldenberg and Feinstein which the non-Hebrew speaking reader without access to the original texts will find greatly illuminating.
(51) For an analysis of the issues surrounding the screening for Tay-Sachs see reference (44):161–170.