

“Testing isn’t the problem”

Views of Muslim theologians, spiritual counsellors, Imams and physicians on preconceptional testing

Amber Bartels & Ghariba Loukili

In the Netherlands, consanguine couples have opportunities to calculate the risks of having a child with a genetic disease. Whilst recognising the fact that some Muslim consanguine couples may be reluctant to be tested because of their religious views, we nevertheless want to offer them this option. In this article, the opinions of Muslim theologians, spiritual counsellors, Imams and physicians in the Netherlands on the possibility of consanguine couples taking a preconceptional test are discussed. From an Islamic point of view, the practice of preconceptional testing cannot be prohibited; on the contrary, our respondents argue that, from an Islamic religious perspective, preconceptional testing is a positive development that can only be encouraged. Using information from Islamic scriptures like the Qur’an, the Hadith, and the opinions espoused by Islamic scholars, the respondents explain why Islam and preconceptional testing go hand-in-hand. The respondents do, however, highlight the dangers of overlooking the ethical consequences that promoting tests such as these might have, and expect some Muslims to be against testing because of their religious (and other) beliefs.

[preconceptional testing, Islam, consanguine marriage, medical ethics, VERWANT]

Introduction

Over the past decade, marriages between kin (consanguineous marriages) have been a topic of great interest in Dutch society. Although the concept of consanguinity includes kin-related marriages of any kind, in practice it usually refers to marriages between cousins or second-cousins. In the Netherlands these occur among people of different ethnic backgrounds of which Moroccan and Turkish ethnic groups are the largest. In 2002, a discussion about the medical implications of consanguineous marriage began in the Dutch media. Experts and non-experts all had ‘their say’ about the risk percentage of having a child with a genetic disease, and over time this became highly exaggerated (Cornel 2003: 3).

In 2009, an alderman of the municipality of Amsterdam, Lodewijk Asscher, even proposed prohibiting marriages between (second) cousins because, according to him, the risk of having a disabled child was too great. Prime Minister Rutte's current government (2012) has plans to ban consanguineous marriages but whether these will be compatible with international and human rights has not yet been determined. However, it was not the political debate that prompted researchers to examine the scope for preconceptional testing, but a medical concern: to give consanguineous couples an opportunity to calculate the risk of having a child with an autosomal recessive disease.¹

Medical experts state that parents who are not kin-related have a 2-3% risk of having a child with a genetic or hereditary disorder; this risk is approximately 2-3% greater for first cousin couples because of their increased risk of having a child with an autosomal recessive disease. This risk, however, is a mean risk; the average is composed of a group of first cousin couples who do not have any increased risk, and first cousin couples who have a 25% risk. Of the total population of first cousin couples, approximately 8-12% carry an autosomal recessive disease, thus only a minority of these couples have a significantly greater risk of having a child with a genetic disease (Waelput & Achterberg 2007: 15; Cornel 2003: 5).

Despite this knowledge, preconceptional and prenatal education for consanguineous couples occurs only infrequently and no method of calculating the exact risk for a specific consanguineous couple has been available. So the department of Clinical Genetics of the VU Medical Centre in Amsterdam launched a research project called VERWANT (which means 'kin' in Dutch),² to develop a preconceptional test method of more precisely determining the risk that a kin-related couple have of bearing a child with an autosomal recessive disease. When this method of preconceptional testing becomes available, it will be essential to draw in the target groups involved, mainly Dutch-Moroccans and Dutch-Turks. Will these groups accept and participate in preconceptional tests? What gains and losses will be made in relation to the application of preconceptional tests? What consequences will couples face when the tests results become clear?

Most Dutch-Moroccans and Dutch-Turks in the Netherlands are Muslim, so the researchers of the VERWANT project agreed that their subjects' decision to participate in preconceptional tests would be based upon (amongst other things) their religious Islamic views. To facilitate the project, the VERWANT researchers therefore proposed that colleagues from the Social and Cultural Anthropology department at the VU University cooperate in the VERWANT project and discuss the significance of any new testing methods with Islamic scholars and counsellors.³ The following research question was formulated: 'What is the Islamic view on preconceptional testing according to Dutch Muslim theologians, Imams, spiritual counsellors and Muslim physicians?'

Other reasons for research on the Islamic perspective regarding preconceptional testing are of broader interest. There is little research in the Netherlands about medical ethical issues and the way Muslims deal with these, while there is much said about the problems surrounding diversity in health services. For years the government in

the Netherlands has been working to improve the accessibility and quality of health care services for migrants (Ingleby 2004). This research project could increase awareness about the dilemmas that may inhibit Muslims from using health services such as preconception and prenatal testing. It could shed light on the dilemmas that might be problematic from a religious point of view or it could show that religious values have no impact and that other reasons must be sought.

In the next section, we briefly reflect on the methodology used in this research. The following section focuses on the research results themselves; first, we examine religious authority in Islam, then the arguments in favour of preconceptional testing are described, subsequently the difficulties that the informants perceive with the introduction of this test are discussed and the recommendations made by the respondents are presented. The article closes with a reasoned conclusion based on the results.

Methodology

To explore the views on preconceptional testing from an Islamic point of view, we chose to work with SPIOR (Stichting Platform Islamitische Organisaties Rijnmond), a well-known platform organization for local Islamic organizations in the Rotterdam/Rijnmond region of the Netherlands. With the help of SPIOR we were able to locate and approach 'experts' of Islam and to find Imams who were well organized, educated and reached a large population of Muslims. Working with SPIOR also enabled us to distribute our findings through a large network.

We decided to question five Muslim theologians, five Muslim spiritual counselors,⁴ three Imams and two Muslim physicians. The experts are of Moroccan (five respondents), Turkish (seven respondents), Dutch (one respondent) and Egyptian origin (two respondents). The decision to invite these particular experts to discuss Islamic views on this subject relates to the particular character of Islamic authority in the Netherlands. There is no single organisation in existence that can speak for all the experts of Islam in the Netherlands, nor is there a fatwa-organization or something of the like.⁵ Muslim theologians, spiritual counsellors and Imams are supposed to be an authority on the theological views of Islamic medical-ethical subjects in the Netherlands, not only because of their knowledge of Islam in general, but because of their particular knowledge of medical issues too. Muslim theologians, for example, are trained in different disciplines, like Qur'an and Hadith science, Islamic jurisprudence, theology and ethics, consequently they have extended and in-depth knowledge of the Islamic sources; expertise which enables them to offer authoritative opinions about Islamic law and ethics for Muslims.

Muslim spiritual counsellors have a significant body of knowledge about Islamic religion, and they know how to relate this knowledge to (practical) ethical issues. They provide care in hospitals, prisons and judicial facilities and understand how Muslims think about, and deal with, genetic counselling and preconceptional testing. This specific combination of religious knowledge and practical experience, particularly in healthcare, enables them to provide answers to questions on preconceptional testing.

The third group of respondents, Imams, have a lot of contact with the target group too, as they preach in mosques and are often the people that Muslims ask about religious issues, daily problems and reproductive issues such as family planning, abortion etc.

Finally, two Muslim physicians were included in the research at a later stage, because of the need for a more applied point of view, especially from a medical perspective. The physicians were questioned mainly about their experiences as physicians and Muslims in practice, and – based on these experiences – how they expected people would react to preconceptional testing.

All the respondents are Sunni Muslims which is the largest group of Muslims across the world and in the Netherlands. Their responses tell us how they think, and how they think an answer would be formulated based on Islamic Sunni legislation. This does not mean that all Sunni Muslims in the Netherlands agree on this topic, nor does it tell us whether they would apply any of their interpretations. In fact, it is quite possible that some Muslims are not even aware of these answers. However, as all the respondents work with Muslims in the field, they are able to anticipate how individual Muslims would react and deal with the issues raised in our questions. These respondents, therefore, are most likely to be able to reflect many of the ideas within Muslim society. Hence, the findings of this research should not be understood to be what Muslims actually do, but rather what Muslims in general (possibly) consider to be normative and ideal.

The fifteen respondents were questioned using semi-structured questionnaires; thirteen interviews were held in Dutch, one in Arabic and one in Berber. The topics and questions were derived from existing literature. Tape-recorded interviews lasted between forty-five and ninety minutes and were transcribed before each text was encoded to produce a structured and logical presentation of the arguments.

Medical-ethical issues in Islam and the methods used by respondents to reach an opinion

We confronted the research respondents with a complex medical-ethical issue for which there is no clear-cut answer to be found in Islamic scriptures like the Qur'an or the Hadith (traditions of the Prophet Muhammad). Hence, it is important to set out how Sunni Muslim experts responded to questions like these. One Muslim spiritual counsellor clearly explained how Islamic 'experts' have to deal with modern issues:

Nowadays, there are numerous things that were not there in the past. The scriptures are limited, when it comes to this. Time and again, new situations occur, so how do we associate with Islam then? The Qur'an contains a lot of guidelines, from which the Muslim scholars extract certain rules. One of these rules, for example, is that when one cannot find the answer to a question in the Qur'an or the Hadiths, our statements have to be founded on *ijma*, consensus. A group of scholars come together, discuss the issue and formulate a statement, which can be seen as a religious statement when all agree on the answer. Another rule for dealing with modern issues is called *qiyas*, analogy. Sup-

pose that we take the Qur'an or the Hadiths to search for a similar situation, with similar circumstances and characteristics. Then we can compare the new situation with the older one and apply the ruling on the old situation to the new situation. Suppose we cannot find such a similar situation, then we use *ijtihad* (interpretation of a scholar). For *ijtihad* the scholar can use different methods like for example *maslaha*, looking for the public interest. Something has to be positive for the general interest, and not in contradiction with the scriptures. Then there is also the method of *istihsan*, the preference. This means a scholar chooses a rule from multiple rules on the same topic which he thinks suits the situation best at that time.

Besides this explanation of how to deal with modern issues, many respondents also mentioned the close cooperation with doctors and physicians. One of the Muslim theologians explained:

I think we have to see doctors and physicians as sources for jurisprudence. In fact, they do know more about medicine and physics than an Imam or scholar in *fiqh*, Islamic jurisprudence, for example. If a scholar wants to launch a statement, he first has to consult a doctor.

Other sources of knowledge about contemporary medical-ethical issues in Islam are the Islamic medical organizations, which are mainly found outside Europe.⁶ In Europe, the European Council for Fatwa and Research (ECFR), which the Netherlands has one representative on,⁷ is probably the highest authority producing statements on medical-ethical issues in Europe. So for Muslim theologians, spiritual counsellors and Imams in the Netherlands, it is important that they keep up to date with the statements issued by the Council and follow developments within different Islamic medical organizations if they want to know when a new statement is being issued. Because the subject of preconceptional testing is relatively new, it is not yet being discussed in these bodies; many respondents however thought that these organizations would pick up on the subject soon.

After the respondents clarified how they determined their answer to an issue, they were asked to formulate their view on the acceptability of preconceptional testing. In the next section, these research results are presented.

Discussion of the research results

During the interviews it soon became clear that all the experts, except one, had quite a positive attitude towards preconceptional testing. The arguments in favour of the testing were mostly drawn from the Hadiths, the Qur'an, and from statements made by modern and former Muslim scholars. In the following section, the respondents' arguments in favour of preconceptional testing are presented. The authors then reflect on the supposed objections to preconceptional testing and, finally, the recommendations made by the respondents are discussed.

Arguments in favour of preconceptional testing

The respondents all cited different sources of substantiation for their arguments in favour of preconceptional testing, but although these sources differed, the arguments themselves were strikingly similar and can be divided roughly into four categories.

First, the possibility of participating in preconceptional testing conforms to the Islamic value of pursuing what is best for the public interest (*maslaha*); all good things have to be encouraged, and all that is good for one's health should be pursued. Two respondents cited two different Qur'an verses: one saying that people should accept what is good for them and leave what is bad for them,⁸ the other that people should not engage in bad behaviour for their own sake, and that of mankind.⁹

More than one respondent adhered to the saying of the Prophet Muhammad: "People should not do harm or evil, and should not render evil for evil."¹⁰ A Muslim spiritual counsellor explained:

In Islam, everything that leads to bad things and evil is disapproved off, and should be dispelled. So everything that brings harm in relation to health or relationships, as well as society as a whole, is not accepted in Islam. It is even the responsibility of people to do something about this. Therefore, people should examine their health to prevent having an unhealthy child.

Another Muslim spiritual counsellor said: "People are given the will to commit themselves to overcome and prevent setbacks. It is not intended that people just abide by a situation."

Second, in Islam it is deemed important to take scientific research seriously and to listen to science, scientists, and doctors and physicians. For example, one Muslim theologian mentioned a Qur'an verse¹¹ which, according to the theologian, could be interpreted as follows: "One is ordered to listen to people who understand a certain issue, especially when one does not have the knowledge by him or herself." This theologian explained that, in regard to preconceptional testing in Islam, no objection of any kind could be found. So if people do not know anything about this, they should listen to physicians. This is something our respondents found very important. "It is a good thing to gain knowledge", the first spiritual counsellor we interviewed underlined. "You know the first revealed verse from the Qur'an? It says that people have to gain knowledge (*'ilm*)."¹²

These remarks are proof that Islam experts can find a positive attitude towards science and scientific research in Islamic scriptures. People are ordered to gain knowledge even before they are ordered to occupy themselves with pious pursuits, as this spiritual counsellor explained. "It is an essential condition in life for Muslims that can be traced back directly to the Qur'an." Gaining information is recommended, as it is one of the aspects of testing, according to this spiritual counsellor:

A preconceptional test provides information, and getting information, as much as possible, is a good thing for every patient. It is important to gain as much knowledge about yourself, the situation and your own health as possible.

This means that Muslims, from their religious point of view, can only accept, respect and appreciate medical testing and research.

Third, Muslims are encouraged to choose their marriage partner carefully. One of the Imams explained: "In Islam, it is a good thing when a man and a woman check their health before they marry. The couple can ask for any test in order to find out if they are in good health." Modern scholars, and scholars of the past, have agreed that it is good to check: "Our scholars take the research of doctors and physicians very seriously," this Imam said. He continued: "God gave us knowledge and this knowledge means, among other things, that we can check whether there is something wrong with us." The Imam told us about the research completed by a professor from Qatar, who is a member of the ECFR and the Islamic Fiqh Council in Makkah, and who states that it is not problematic in Islam for people to want to undergo medical tests before marriage and that a preconceptional test can help potential husbands and wives to know whether they make a good match, or if they form a high-risk couple. If the latter is the case, they could endanger the life of their child. This knowledge puts them in a very difficult position in which they have to deal with many ethical issues.

One of the Muslim theologians related the argument to older teachings and a quotation made by a former scholar who founded the third Islamic law school *madhhab*, Muhammad b. Idris al-Shafi'i. He preached that one has to search carefully for the one he or she wants to marry. One has to check whether the partner is healthy, the family healthy, whether the intended spouse comes from a good environment etc., and one even has to check the persons social contacts.¹³ Two respondents, a Muslim spiritual counsellor and a theologian both mentioned a saying (traced back to the Prophet Muhammad)¹⁴ that one must search for a healthy person to marry, explaining that these kinds of sayings are related to the offspring's right to have a healthy start in life.

The final category of argument states that undergoing preconceptional testing conforms to the *maqasid-al-sharia*, or the objectives of Islamic law. One of these objectives states that life needs to be protected. This is also explained by the statement, mentioned by one of the respondents, that all the doors to any dangers should be closed. In other words: acts which can bring about harm in the future should be avoided. One of the Muslim theologians said: "An unborn child has the right to be born healthy. If being born in an unhealthy condition can be avoided by the parents in any way, they should try to do this." One of the Imams, in a similar manner, said that he thought the possibility of participating in preconceptional testing was a positive development as well, because it could improve peoples' health. "It is a good thing to bring more healthy children into the world, which should be the intention of mankind." All the spiritual counsellors, Imams and theologians declared that they advocate everything that contributes to healthier people.

Supposed objections to preconceptional testing

Although it is striking how positive the religious experts' attitudes are towards preconceptional test, they often caution that it is by no means certain that the Muslim population in Dutch society would welcome these tests. Most of the respondents expected many Muslims to claim that preconceptional testing went against the will of God. According to the respondents, however, this claim is not true. A Muslim spiritual counsellor explained: "People will often say that it does not matter what child they receive, because everything comes from God, and so it is good." The point is, according to these respondents, that a relatively large proportion of the Muslim population in the Netherlands lack knowledge about Islam in relation to ethical questions and medical practices such as these. Because of this lack of knowledge, they resort to certain Qur'an verses or other sources without fully understanding the content and without searching for more knowledge on these subjects. They think that testing is not allowed, because they see testing as going against the will of God. An argument supporting this can be found in the Qur'an which says that only God knows what is in the womb.¹⁵ The respondents, however, emphasized that this does not mean that a couple should not explore the risk percentage of having a disabled child.

Patterns of tradition can also restrain people from participating in preconceptional testing. Several respondents explain:

It is very common to marry inside the family and to think one will receive healthy children. This is due to the fact that people see a lot of consanguineous marriages around them which produces 'healthy-looking' children. Therefore, people continue marrying within the family and are not engaged in searching for solutions.¹⁶

This problem can be countered by providing as much information as possible, which we will elaborate upon below. What matters here are the ethical consequences of the test results, as one of the Muslim theologians said: "Testing isn't the problem. The only problem is the results a test produces." If, for example, a test indicates that a couple has a high risk, what should they do? Should they separate and find a new partner? Should they take the risk and try to become pregnant? If they become pregnant and the foetus is found to be disabled, is abortion an option for that couple? Should they stay together and decide not to have children? These difficult questions are vital and must be considered when introducing preconceptional tests.

Recommendations

When discussing how to introduce preconceptional testing and how to inform people about the medical options, many respondents immediately emphasized that this should not be related to the political debate taking place on consanguineous marriages. These tests are not related to the decision to marry within the family; discussions about marriage in the family and about family marriages and migration

limitations should be avoided. The aim of the test is to provide consanguineous couples with better information about the risks of having a disabled child. Whether a consanguineous couple wants to take a test is their own choice. If preconceptional testing ever became an obligation, this could be seen as going against Islamic thinking, because medical decisions like this should be an individual's own choice, so the respondents emphasized.

There are a number of things to be taken into account when testing is offered in practice. First, people have to be very well informed about the procedures, the benefits, the possible consequences of testing and the outcomes. This information could be provided by the internet, flyers and brochures, for example. The Imams of mosques could also play a role by organising special information sessions for both women and men. All the respondents emphasized the importance of the cooperation between Islam experts and physicians, stating that it has proven to be very productive in Islamic countries and that many medical issues are relatively new and clear answers are not always available. Muslim scholars have to study and interpret old sources and, with the assistance of physicians, relate these to new medical scenarios and produce reasoned answers.

Conclusion

In this article we have seen that Muslim theologians, Imams, spiritual counsellors and Muslim physicians approve of preconceptional testing. Based on the sacred scriptures of Islam, they argued that preconceptional testing should only be encouraged. However, it has become clear that there is more to testing than simply the test itself and that testing can have far-reaching ethical and emotional consequences. It is, therefore, very important to make sure that the individuals being tested are well informed about the procedures and consequences and, to achieve this, it is important for Islamic and medical experts to cooperate closely. At a conference on Islam and Bioethics, held in the USA in 2006, it was stated that western knowledge about medical ethical considerations for Muslims is limited.¹⁷ In addition, the literature illustrates that, in western countries, the lack of knowledge about different ethical viewpoints is causing problems, especially in relation to research projects concerning medical ethics.¹⁸ This means that there is more work to be done than just raising awareness. Islamic opinions on medical questions also need to be known by western physicians; it is not only the Muslim population in western countries who should take responsibility. Physicians who are in direct contact with Muslim patients should be very well informed too.

There are many different medical ethical views and principles in existence all over the world. These ethics develop throughout history and are based upon culture, economics, biology, philosophy and religion.¹⁹ Differences in the medical ethical views between people of disparate backgrounds can cause problems in countries where ethnic groups co-exist. The medical ethics of minority groups are often ignored as the larger, dominant group has little, or no, understanding of them and creates national

health services which are based upon its own values and ethics.²⁰ As we explained in the introduction, consanguineous marriages receive a lot of negative attention and criticism in the Netherlands. We would like to turn away from this, and emphasize the right that a population has for medical services which take into consideration all the different medical ethical perspectives of the society it serves. Consanguineous couples should be well informed about the decisions they make, without negative judgments being made. By showing how important Muslim leaders think these issues are, we hope to have made a first step towards raising awareness of these ethical questions and stimulating discussion about them. They are, after all, issues which should be on the agenda of every multicultural society that Muslims form a part of.

Notes

Amber Bartels, MSc, studied Social and Cultural Anthropology and Ghariba Loukili, MA, Religious Studies and Social and Cultural Anthropology, both at the VU University in Amsterdam. bartelsamber@hotmail.com; g_loukili@hotmail.com.

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- 1 An autosomal recessive disease only occurs if both parents transmit a mutated gene to their child. The parents, who are called carriers, have one mutated gene each. One of the most common autosomal recessive diseases is called hemoglobinopathy, a collective name for different kinds of hereditary anemia. Other examples are metabolic diseases, cystic fibrosis, and certain disorders involving hearing or vision problems, skeletal abnormalities and mental retardation.
- 2 www.verwant.info.
- 3 The research for this article is part of the research on consanguinity in the Netherlands conducted by Dr. E. Bartels, O. Storms MSc. Dr. Petra Verdonk, Drs. Suzanne Metselaar, Tamar Pagrach MSc. founded by CSG (Centre for Society and Life Sciences) Nijmegen, in cooperation with Marieke Teeuw MD, PhD Community Genetics VUmc.
- 4 In the Netherlands there is one title for spiritual counsellors who work in medical centres and/or detention centres. In English both 'spiritual counsellors' and 'chaplains' are used. We opted for 'spiritual counsellor.'
- 5 In the Netherlands, different experts on Islamic thought work for different organizations. They can be found at universities, medical centres and in the government, for example, but they also work in mosques and non-governmental organizations etc., so are not united in one organization representing one Islamic voice.
- 6 A well-known organization on medical ethics within the Muslim world is the *Islamic Organization for Medical Sciences* (IOMS). For their role in reviving Islamic medical ethics, see Abdul Rahman A. al-Awadi, "The Role of the Islamic Organization for Medical Sciences in Reviving Islamic Medicine", in: *JIMA* 32 (2000), p. 68-72.
- 7 This is also one of the Imams whom we interviewed.
- 8 *Surah (chapter) 7, aya (verse) 157*: (...) He will enjoin on them that which is right and forbid them that which is wrong. He will make lawful for them all good things and prohibit

- for them only the foul; (...). Qur'an translation referred to by M. Pickthall. <http://www.islam101.com/Qur'an/QTP/index.htm>.
- 9 *Surah 2, aya 195*: Spend your wealth for the cause of Allah, and be not cast by your own hands to ruin; and do good. Love Allah loves the beneficent. Qur'an Translation as note 9.
 - 10 This *hadith*: '*Lâ darar wa lâ dirâr*' is stated in the 40 *hadiths* of the famous medieval scholar al-Nawawi (d.1277 AD) under number 32 and can be found online: http://www.40hadith.com/40hadith_en.htm. This collection of *hadiths* presents general important sayings of the Prophet Muhammad that concern all Muslims.
 - 11 *Surah 21, aya 7*: (...) the followers of the Reminder if ye know not? Qur'an Translation as note 9.
 - 12 This respondent explained that this chapter in the Qur'an speaks about the importance of knowledge. He refers to *sura 96*. Qur'an Translation as note 9.
 - 13 This saying and similar sayings of the second caliph 'Umar b. al-Khattab have been raised in several interviews. Not every respondent is certain if this saying is correctly ascribed to 'Umar; some respondents are even sure that these sayings are not his at all. Moreover, scholars around the world explained that these sayings are based upon an unauthentic saying ascribed to the Prophet. More on this subject can be found in *Islam and Disability. Perspectives in theory and jurisprudence*, by Mohammed Ghaly (2010: 119-121).
 - 14 Both respondents who mentioned these saying were not able to give a clear source for it. Afterwards the saying was not easily to be found in *Hadith* literature and it became clear that this also is a saying without a strong base.
 - 15 *Surah 13, aya 8*: Allah knows that which every female bears and that which the wombs absorb and that which they grow. And everything with Him is measured. Qur'an Translation as note 9.
 - 16 The assumption is that lack of knowledge about certain diseases related to kin related couples, means they are not always recognized as diseases. People often think that the children around them are healthy and that they do not need to worry about consanguine marriages. This opinion is based on one of the researcher's own evaluations.
 - 17 Islam and Bioethics: Concerns, Challenges and Responses', held in Pennsylvania State University on the 27th and 28th of March 2006 (in Brockopp 2008).
 - 18 Brockopp 2008.
 - 19 Rispler-Chaim 1989.
 - 20 Gatrad & Sheikh 2001.

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