Sundhedsstyrelsen
National Board of Health

SCREENING FOR HAEMOGLOBIN DISORDERS AMONG PREGNANT IMMIGRANTS

– a health technology assessment

Summary

2009

Danish Health Technology Assessment – funded projects 2009; 9(3)

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Summary

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Danish Health Technology Assessment – funded projects 2009; 9(3)

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URL: http://www.dacehta.dk

Key words: health technology assessment, HTA, thalassaemia, sickle cell, screening, prenatal diagnosis, immigrants, pregnancy, screening, immigrant

Language: English summary of the full report in danish

Format: Pdf
Version: 1,0
Version date: May 13 2009

Issued by: National Board of Health, Denmark, June 2009

Category: Advisory

Design: National Board of Health and 1508 A/S
Layout: Schultz Grafisk

ISBN (electronic version): 978-87-7676-925-3
ISSN (electronic version): 1601-586X

This report should be cited as follows:
Hvas A-M, Ehlers L, Møller HJ.
Danish Centre for Health Technology Assessment, National Board of Health
Screening for haemoglobin disorders among pregnant immigrants – a health technology assessment
Copenhagen: National Board of Health, Danish Centre for Health Technology Assessment, 2009
Health Technology Assessment 2009; 9(3)

Series Title: Danish Health Technology Assessment – Projects Funded by DACEHTA

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Summary

This health technology assessment (HTA) was made to assess the evidence for and consequences of introducing a screening programme for haemoglobinopathy among pregnant immigrants in Denmark.

The HTA initially describes the clinical, epidemiological, etiological, diagnostic, prognostic, and treatment-related aspects of haemoglobinopathy. Subsequently, the report evaluates the patient aspect from an ethical perspective and a description of the attitudes to prenatal diagnosis and to termination of pregnancy among female immigrants. Advantages and disadvantages of different organisational models are presented and discussed primarily on the basis of a comparative analysis of the conditions in England and in the capital area of Copenhagen in Denmark. Finally, the report offers an analysis of and a systematic review of national and international literature regarding economical implications of introducing a screening programme.

Since 1995, there has been a screening programme for haemoglobinopathy among pregnant immigrants in the Copenhagen area. However, the programme has not been subject to an HTA. In 2005 a screening programme was established in a larger regional area in Denmark. The present HTA assesses the evidence for such a programme as well as the results of implementing the screening programme.

Technology and description of disease

Why a screening programme?

Haemoglobinopathies are hereditary haemoglobin diseases. These diseases are often associated with high morbidity and mortality if the diseased gene is inherited from both parents. Haemoglobinopaties may cause severe anaemia, bone changes and bone pain as well as splenomegaly and may induce risk of thrombosis. Due to immigration into Denmark from countries where haemoglobinopathy is a relatively frequent disease, it is on the basis of the screening criteria of the World Health Organisation (WHO) relevant to consider screening of pregnant immigrants for haemoglobinopathy in Denmark.

Who should be investigated?

A systematic literature review indicates that it is relevant to examine women coming from the countries mentioned below for haemoglobinopathy, if not previously examined, at the first pre-natal examination:

The Mediterranean area, Iran, Iraq, Pakistan, Africa (or of African origin), The Middle East, India, and Southeast Asia.

What should the screening programme contain?

According to international guidelines it is relevant to identify the following haemoglobinopathies:

a. Heterozygote forms of β-thalassemia, α-thalassemia, Haemoglobin S, Haemoglobin C and Haemoglobin E

b. Homozygote and double heterozygote conditions with genotype β-thalassemia major, α-thalassemia/Haemoglobin E disease, sickle-cell anaemia (Haemoglobin S/Haemoglobin S, β-thalassemia/Haemoglobin S, Haemoglobin S/Haemoglobin C)
c. Haemoglobin D, Haemoglobin H and Haemoglobin O-Arab.

In Denmark, it is possible to establish a selective screening programme that complies with the above criteria as the technology for this screening is valid and accessible.

Assessment of the patient aspect

The patient aspect involves several problems:

- Female immigrants' attitude towards prenatal screening
- Female immigrants' attitude towards induced abortion
- The timing of screening.

Attitude to prenatal screening and induced abortion

In general, female immigrants have a positive attitude to prenatal diagnosis for haemoglobinopathies. However, this attitude is not necessarily related to a decision on termination of the pregnancy.

The abortion ratio among female immigrants is considerably higher compared to ethnic Danish women. The reasons for this are unclear but a part of the explanation could be scarce knowledge of sexuality and contraceptive methods among female immigrants. Further identification of the background for ethical differences concerning contraception and abortion seems relevant.

Timing of prenatal screening

Concerning timing of screening the results of this HTA show that 75 % of the female immigrants were examined for haemoglobinopathy in the first trimester, and 61 % had the test performed before the end of gestational week ten. It is thus an acceptable part of the women that have the possibility to choose an abortion.

Organisational perspectives

In connection with this HTA we have developed a model that can be implemented in Denmark outside the capital area of Copenhagen.

Blood sampling and communication of the test result

A blood sample is taken at the first prenatal visit at the general practitioner. Analysis of fractionated haemoglobin and erythrocyte mean cell volume is performed at a local laboratory if possible. Due to the time factor it is important with a close collaboration between the general practitioner and the departments of clinical biochemistry.

If the pregnant woman does not carry a haemoglobinopathy, the test result is send electronically to the general practitioner. If the woman carries a haemoglobinopathy, the father of the child is offered an examination as soon as possible. If both parents carry a haemoglobinopathy, a molecular genetic test is performed and the couple is admitted to further consultancy at the department of gynecology/obstetrics and clinical genetics. On the basis of the decision of the parents a biopsy from placenta is taken to decide whether the fetus will have a severe haemoglobinpathy.

Results after three years of screening

The prevalence of haemoglobinopathy among screened women was around 2 %. This rather low prevalence is partly explained by mistaken referrals of ethnic Danish women, and this lead to an under-estimation of the prevalence among immigrant women. Finally, we found that only approximately a third of the women who according to the programme should have been examined had actually been examined for haemoglobinopathy.

During the project period, no children homozygous for haemoglobinopathy were born or diagnosed in the Central Denmark Region (1.2 M inhabitants).

Organisational challenges

From an organisational perspective the HTA points to the following problems:

- It is an organisational challenge to make sure that all relevant examinations are conducted before the 12th gestational week.
- The implementation of the screening programme was not optimal as only one third of the women who should have been examined were actually examined. Some referrals were irrelevant (males, ethnic Danish women). The HTA thus leaves an open question on how to ensure optimal implementation of the screening programme in general practice.
- Furthermore, there is a need for clarification of how to manage the information to the female immigrants.

Economy

The literature review of the health-economic analyses shows that screening of pregnant immigrants is cost-effective in similar English populations.

The expected costs in Denmark for screening all pregnant immigrants are estimated to approximately DKK 2.6 M annually. The costs saved by the healthcare system per unborn infant with haemoglobinopathy are approximately DKK 1.2 M on average. This amount only covers hospital admissions and the costs would thus be higher if adding costs of bone marrow transplantation, the very expensive medicine and for help from e.g. the municipality.

A rough estimate concludes that it is cost-effective to establish and run a screening programme in the parts of Denmark with a relatively high number of immigrants if two diseased foetuses are aborted annually. On the basis of a literature review eight abortions are estimated annually in Denmark. In conclusion, a screening programme as described in the section *Technology* is expected to be cost-effective.

The aim of the present HTA is to provide professional advice on prenatal diagnosis of haemoglobinopathies in pregnant immigrants. The present report is a contribution to the continuous work of the Danish National Board of Health within maternity welfare.

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