

Genetic counselling

Introduction

In this activity students will first carry out research into sickle cell and beta thalassaemia and will then watch (or read transcripts from) a number of short clips of people talking about their feelings when they were screened for these genetic diseases.

They will then role play a genetic counselling session taking the role of either the pregnant woman/partner, or a genetic counsellor.

The whole activity will take at least 1 lesson (although some of the research could be set for homework in a prior lesson).

The activity

Part 1:

In pairs students research and summarise the symptoms and genetics of sickle cell and beta thalassaemia. The NHS website (www.nhs.uk) and the BBC website (www.bbc.co.uk/health) are good places to start their research.

Part 2:

It is important for health professionals that they are aware of the issues, worries and concerns felt by the people who are being screened for the disease. The website [Health Talk Online](http://www.healthtalkonline.org) has a large number of interviews with people who have been affected by different aspects of health and illness, not just in pregnancy. Students should listen to a number of the interviews and summarise some of the common features of the experiences. A number of questions are provided for the students to do this, and you may wish them to use a graphic organiser such as a spider diagram to help them organise their thoughts.

To access the experiences go to [http://www.healthtalkonline.org/Pregnancy children/Screening for sickle cell and beta thalassaemia](http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia). Students should then watch at least two clips from each of the following categories (which can be accessed by clicking on the 'talking about' menu):

1. Understanding the condition
2. Views about screening
3. Carrier screening during or before pregnancy
4. Diagnostic tests in pregnancy
5. Information and communication with professionals

How science works

Hh, Some new technologies and new areas of scientific research raise ethical issues. That is to say, they raise questions about whether a particular action is right or wrong.

Hk A utilitarian approach is to argue that the right decision or choice is the one that leads to the greatest good for the largest number. It can also be argued, however, that some actions are wrong, even if they lead to good outcomes.

Hi Scientists have an individual responsibility to ensure that their practice is ethical. This may be detailed in a professional ethical code. Such codes may also form the basis of regulatory decision by ethics committees. National or international regulations that apply to scientific activity may have an ethical basis.

Science explanations

Ca, Instructions for development are found in the form of genes which are part of the chromosomes in the nucleus of every cell in the organism. Chromosomes contain a large number of genes. All cells except sex cells, and red blood cells, contain two sets of chromosomes. Both chromosomes in a pair carry the same genes in the same place, but the two chromosomes may carry slightly different versions, called alleles.

Cd Each cell contains two genes with the same function, and each gene may occur in two or more different versions called alleles. The way one allele affects cell function may dominate the effects of other alleles. This allele is known as dominant, and the others as recessive alleles. The effects of recessive alleles are only seen if both chromosomes carry the recessive allele.

Part 3:

Working in pairs or threes students will now use the information from activities 1 and 2 to role play a counselling session. One student will act as the genetic counsellor and the other student/s will act as the pregnant couple. The first time the role play is carried out sickle cell testing will be discussed, and then the students can swap over and discuss beta thalassaemia testing.

Plenary:

As a class debrief the role play. Ask the students questions such as:

- Pregnant couple - in role, how did you feel about the way that the counsellor talked to you? What was helpful? What, if anything, made you feel bad?
- Counsellor - in role, how hard was it to explain the genetics in a simple, yet correct, way? What did you find was the best way to approach it?
- What information did the counsellor need?
- How much information would you need if you were the pregnant couple?
- Would a single session of counselling be enough?
- What is the value of having a separate counsellor, instead of the GP, midwife or obstetrician?

This link is to the current NHS publication which explains what screening tests may take place during pregnancy. http://www.screening.nhs.uk/anpublications/screening_tests.pdf



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During pregnancy a number of tests may be carried out. These include tests for infections such as HIV and Rubella as well as for inherited genetic diseases. In this activity you are going to carry out research into two such genetic diseases and listen to experiences of people who have had the tests. You will then use your knowledge to role play a genetic counselling session.

Part 1. Sickle cell and beta thalassaemia

Working in pairs find out about the two genetic diseases Sickle cell and beta thalassaemia. For each condition you should find out:

- What is the disease
- What are the symptoms and what consequences are there of inheriting the condition
- Who is most at risk from the condition.
- How they are passed on - including a diagram showing a genetic family tree.
- How are they tested for and how accurate are the tests.

Your teacher may provide you with information and suitable websites to use.

Part 2. Experiences of people with the conditions

It is important for health professionals that they are aware of the issues, worries and concerns felt by the people who are being screened for the disease.

[Health Talk Online](#) has interviews with a large number of patients about their experiences of health and illness, not just in pregnancy. In this part of the activity you are going to watch some of the clips (or read a transcript if audio facilities are unavailable) to see how people have reacted to testing for sickle cell and beta thalassaemia.

As you are watching make notes on the following:

- Why did the people want to be tested?
- How did they react when they received the results of the tests?
- How did it affect their relationships with other members of the family?
- What did they decide to do about the results of the tests?
- How did the medical staff help/hinder them?

Watch at least two clips from the following categories:

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http://www.healthtalkonline.org/Pregnancy_children/Screening_for_sickle_cell_and_beta_thalassaemia and click on the 'talking about' menu.

Part 3. Genetic Counselling

A genetic counsellor is a trained health professional who will meet with people and families at risk from genetic conditions.

The counsellor will help people to understand the genetic condition, how they inherited it, and the consequences for their (and their families) lives. They will also help people to deal with the strong emotions that are often present when a diagnosis is given.

To be a counsellor you have to have a good understanding of the science and genetics of a range of conditions, but you also have to be able to explain the ideas in an easily understandable way.

Scenario:

Maria has just been to see her GP as she is 8 weeks pregnant. As her father is originally from Cyprus, Maria has been asked if she and her husband would like to be tested for sickle cell and beta thalassaemia. They have also been referred to a genetic counsellor to talk about what a positive result of the test would mean for them.

Working in pairs or threes you will be either a genetic counsellor or Maria (or her husband) and will role play the first counselling session.

Role guide: Maria and husband

You are very happy to be expecting a child, but are worried about the blood tests and results. You need to know what the diseases are, and what the consequences are for you and the baby if the test results are positive.

Role guide: Genetic Counsellor

You must explain to Maria and/or her husband what sickle cell is and how it is passed on from parent to child. You will need to discuss the implications for the health of the baby if the test results are positive. You may also want to talk about having other members of the family tested for the conditions. You will need to be realistic about the results, but reassuring as well.

Now swap roles and repeat the role play, but this time explain what beta thalassaemia is, and what the consequences are.

Plenary: As a class you will now debrief your role-play. Be prepared to discuss how you felt whilst playing the role, as well as thinking about the value of similar counselling sessions in real life.