PACES Station 4: COMMUNICATION SKILLS & ETHICS

Your role: You are the doctor on the ward

Problem: Discussing the implications of Huntington’s disease with a relative

Patient: Mrs Jean Smith, a 55-year-old woman

Relative: Mrs Susan Robinson, the patient’s 35-year-old daughter

Please read the scenario printed below. When the bell sounds, enter the room. You have 14 minutes for your consultation with the patient/relative, 1 minute to collect your thoughts and 5 minutes for discussion. You may make notes if you wish.

Where relevant, assume you have the patient’s consent to discuss their condition with the relative/surrogate.

Scenario:
You are about to meet the daughter of a patient who was admitted yesterday having taken an overdose of antidepressants and alcohol. The patient is now recovering with supportive therapy. Her daughter is visiting for the first time and is very anxious to see a doctor to discuss the situation.

The hospital notes show that the patient attended a neurology clinic 2 months previously for the assessment of involuntary movements and altered personality. A clinical diagnosis of Huntington’s disease was made by the consultant neurologist and this has been confirmed by a blood test. Unfortunately she did not attend her follow-up appointment for discussion of the results with the neurologist.

The patient was seen by your consultant on the post-take ward round earlier in the day. During the ward round, the consultant commented that Huntington’s disease was an autosomal dominant disorder characterised by chorea, progressive dementia, and premature death in all affected individuals.

From the medical notes you see that the patient’s father died aged 60. He was in psychiatric care with an undiagnosed illness before his death. The patient has three adult children, and the daughter you are about to see is the eldest. She has two children of her own.

**Your task** is to explain the diagnosis of Huntington’s disease to the patient’s daughter and discuss with her the implications of this for the rest of the family.

DO NOT EXAMINE THE PATIENT
DO NOT TAKE A HISTORY
Any notes you make must be handed to the examiners at the end of the station.
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Your role: You are Mrs Susan Robinson, the patient’s 35-year-old daughter
Problem: Discussing the implications of Huntington’s disease with a relative
Patient: Mrs Jean Smith, a 55-year-old woman

Scenario:
Your mother was admitted to hospital yesterday, apparently having taken an overdose of antidepressant tablets and alcohol. You live with your own family, which is a considerable distance from your mother, and this is the first opportunity you have had to visit. You are anxious to know what is going on and you have asked the nurses if you could speak to a doctor. They have arranged for you meet a member of the medical team looking after your mother.

Because of the distance you live away from your mother, you do not see her very often, but you speak to her on the phone from time to time. You are aware that over the past 5 years she has become more forgetful, and that she does not take as much care over her appearance as she did in the past. Her family doctor considered she might be depressed and has made attempts to treat this with courses of tablets. Your mother has also developed a habit of making sudden purposeless movements of her arms and legs. You know that 2 months ago she was seen by a specialist at the hospital, but when you spoke to her on the phone about this afterwards, she told you the specialist did not think there was any serious problem.

Given that you have come to the hospital to discuss your mother’s recovery from her overdose, you will be surprised when the doctor tells you that she has been diagnosed with Huntington’s disease. You know nothing about this disorder and you ask the doctor to explain it to you. You will become very anxious and upset when you are told it is an incurable disease which runs within families. You are told that it affects about half of the family members, and results in uncontrolled movements of arms and legs and progressive loss of mental function before an early death. There is no way of preventing this outcome.

Your mother’s father died in long-term psychiatric care aged 60 and had problems with fidgeting, self-neglect, and depression. Before being admitted to the psychiatric hospital, he made unwanted sexual advances to several people, and because of the embarrassment caused by this, his illness has never been discussed openly in the family. As far as you are aware, no other members of the family have any similar problems and you are in good health yourself. You are now very anxious because of your grandfather’s history and because you have seen your mother gradually deteriorate over the past 5 years.

You are the oldest of your mother’s three children. You have a sister aged 32, who has a 5-year-old daughter of her own, and a brother aged 25 who is about to be married. You have an 8-year-old daughter and a 10-year-old son yourself. Your concern at the moment is that you and your children may develop Huntington’s disease. You are also worried for the rest of your family. You want to
know what the chances of developing this disease actually are, and if any tests can be done to identify those family members who are going to be victims of the disease. You want any test available to be done without delay, for yourself, other members of your family, and especially for your children.

**Attitude and emotional responses**
You want to know as much as possible about this condition. When the doctor explains what is involved, you become greatly shocked and upset. Your anxiety is so great that you want the doctor to take blood from you right now for testing. You will be calmed if the situation is explained clearly and sympathetically.

**Make sure you ask the following question:**
- Does this mean I might go insane and behave as my grandfather did before he died?

**Other questions you might like to ask include:**
- Can the effects of this disease be prevented from developing?
- Is there any treatment that can help?
- Is there a test to show which of us will develop this disease?
- Can I have the test now?
- Can my children be tested?
- What could be the disadvantage of being tested?
Examiners should advise candidates when there are 2 minutes remaining (i.e. after 12 minutes). If the candidate appears to have finished early remind them how long is left at the station and enquire if there is anything else they would like to ask, or whether they have finished. If they have finished, please remain silent and allow the candidate that time for reflection. The surrogate should remain until the end of the 14-minute period.

A good candidate would be expected to have agreed a summary plan of action with the subject before closure. Nonetheless, in discussion, the examiners will usually ask the candidate (after one minute’s reflection) to summarise the problems raised in the foregoing exchange.

The candidate should be asked to identify the ethical and/or legal issues raised in this case and how they would address them. The framework for discussion should include consideration of these four underlying principles:

- Respect for the patient’s autonomy
- Duty to do good
- Duty to do no harm
- Legal aspects (a detailed knowledge of medical law is not required)

Candidates are not expected to have a detailed knowledge of medical jurisprudence. For overseas candidates in the UK, detailed knowledge of UK law is not required, although candidates should be aware of general legal and ethical principles that may affect the case in question.

The candidate should recognise his/her limit in dealing with a problem and know when, and from where, to seek further advice and support.

Examiners should refer to the marking guidelines in the four skill domains on the marksheet.

Examiners are reminded that, during the calibration process, the surrogate should be rehearsed and specific aspects of the scenario that require clarification or emphasis should be discussed. The boxes on the next page indicate areas of potential interest in this case which both examiners should consider, along with any other areas they feel appropriate. Examiners must agree the issues that a candidate should address to achieve a Satisfactory award for each skill and record these on the calibration sheet provided. Examiners should also agree the criteria for an Unsatisfactory award at each skill.
Problem: Discussing the implications of Huntington’s disease with a relative
Candidate’s role: The doctor on the ward
Surrogate’s role: Mrs Susan Robinson, the patient’s 35-year-old daughter
Patient’s role: Mrs Jean Smith, a 55-year-old woman

Examiners are reminded the areas below indicate areas of potential interest, but are not intended as absolute determiners of Satisfactory performance. It is for the examiners to agree and record the specific criteria they will assess the candidate on during the calibration process.

During the interview please use the following question to explore aspects of communication and ethical interest:

- What factors did you take into account when answering the patient’s question about the risks for her and her children?

Clinical Communication Skills (Clinical Skill C)
- Describes the prognosis and likely rate of decline in a patient with Huntington’s disease
- Recognises the daughter’s anxiety and empathises with her situation
- Explain the inheritance of Huntington’s disease

Managing Patients’ Concerns (Clinical Skill F)
- Acknowledges the daughter’s fears and discuss the need for genetic counselling before considering presymptomatic testing

Clinical Judgement (Clinical Skill E) (also points of ethical interest)
- Provides an outline of the difficulties a presymptomatic individual might encounter once he/she is known to have Huntington’s disease
- Acknowledges the ethical issues involved with the testing for an incurable disorder of children who are too young to give consent
- Good candidates might discuss the role of symptomatic management for patients with Huntington’s disease

Maintaining Patient Welfare (Clinical Skill G)
See marksheet