Helping People with Mental Illness

A Mental Health Training Programme for Community Health Workers

Module E

Helping Families Cope with Mental Health Problems
Helping People with Mental Illness

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About this course

This course is designed to help Community Health Workers with some of their day to day work. It was developed after consultation with Community Health Workers, Health and Social Care Forum members, psychiatric nurses and lecturers at the University of Port Elizabeth. We have tried to understand the needs of both community health workers and members of Township communities who suffer from or care for people with mental illness.

We have based the whole course on the idea that people with mental illness are vulnerable to stress. Stress can have a powerful effect on mental health. Helping people with mental health problems and those that care for them to reduce stress can be very helpful indeed. We hope this approach will be useful to Community Health Workers.

The course consists of eight modules on different topics in mental health. There are introduction modules and modules on helping people with their drug treatments, other ways to manage mental health problems and a module on how to assist with tracing people who default from the mental health services. It is possible to design your own course by picking from these modules. It is not necessary to use all eight modules. On the next page we make some suggestions as to how different courses might use the different modules.

The course is a ‘train the trainers’ course so each module contains:

- A plan of each module divided into ‘activities’
- Clear instructions on how to teach the module including resources needed
- A set of full size photocopies of all the slides used to teach the course.

We hope that Community Health Workers in communities, their colleagues and most importantly South Africans with mental health problems gain something positive for themselves from the course. We wish you luck with all your endeavours.

David Richards
Tim Bradshaw
Hilary Mairs
The University of Manchester, UK. November 2003.
Helping People With Mental Illness

Course Outline

There are eight modules in this course. They are:

- **Module A**: What is Mental Illness?
- **Module A2**: Introduction to the Treatment of Mental Health Problems
- **Module B**: Understanding Mental Illness
- **Module C**: Responding to People with Mental Health Problems
- **Module D**: Drug Treatments and Mental Illness
- **Module E**: Helping Families Cope with Mental Health Problems
- **Module F**: Living Well with Mental Health Problems
- **Module G**: Tracing People who Default from Mental Health Services

The course is very flexible. It is not necessary to teach all eight modules. Some modules contain similar material organised in a different way to suit different courses.

Organising a Course

Below are suggestions for three different types of courses:

1. **A course to introduce people to some basic knowledge about mental illness and how to talk to people who have mental health problems**
   - Modules A, B and C

2. **A course to prepare volunteers to assist medical and nursing staff trace people with mental health problems who have defaulted from their clinic appointments**
   - Modules A2, C and G

3. **A comprehensive course for volunteers who want to work with people with mental illness in the community**
   - Modules A, B, C, D, E, F

Each module lasts three or three and a half hours. The instructions are easy to follow and all the materials are included in each pack. Although it is not necessary to take all the modules the ones chosen for any course should be taken in the order above. They can be spaced out over days or weeks or run together over a few days. The materials are designed so that an ordinary person can use them to train other people. You do not have to be an expert to teach this course. However, you should have done the course yourself before you can become a trainer.
Module E

Helping Families Cope with Mental Health Problems

Introduction

- This module introduces the role of families and how their behaviour can both increase and reduce stress for people with mental health problems

Purpose

- Consider the role of families in caring for mentally ill people in the community
- Discuss the importance of families having an understanding of mental illness and the patients behaviour
- Highlight behaviours of family members that may increase stress for the patient
- Describe helpful behaviours of family members that reduce stress for the patient

Materials

- Slides E1 – E9
- Flip chart or chalkboard
- Flip chart pens or chalk
- Pens and Paper
- Handout sheets
- Case study E1 for Sipho and family

Activities

Activity 1: Introduction 10 minutes
Activity 2: Role of families in supporting the mentally ill 30 minutes
Activity 3: Behaviour by family members that may increase stress for the patient 50 minutes
Activity 4: Understanding the effects of family environments within the framework of the ‘higher chance’ model. 15 minutes
Activity 5: Behaviour by family members that may reduce stress for the patient 15 minutes
Activity 6: Providing support to families 50 minutes
Activity 7: What Have We Learnt? 10 minutes

Overall Time Needed Three hours
Activity 1:  Introduction  10 minutes

Method

- Presentation

Use slide E1 to start the activity

**Module E:**

**Helping Families Cope with Mental Health Problems**

Explain that this module is important because much of the care provided for people living in the community who suffer from severe mental illness is provided by family members and therefore it is important that we provide the best available support to these families. Also it has been shown that although the vast majority of families are very caring and genuinely want to do what is best for the patient. Without help to understand mental illness and how to respond to the patient’s behaviour they may unintentionally behave in a way that causes stress for the patient and makes it more likely that they will become ill again. If families receive adequate information and support they can help to reduce stress for the patient and make it less likely that they will become ill again.

Use slide E2 to outline the aims of the module:

**AIMS**

- Consider the role of families in caring for mentally ill people in the community
- Discuss the importance of families having an understanding of mental illness and the patients behaviour
- Highlight behaviours of family members that may increase stress for the patient
- Describe helpful behaviours of family members that reduce stress for the patient
Activity 2: Role of families 30 minutes

Methods
- Presentation
- Large Group Discussion

This activity is used to review the role of families in caring for someone who is suffering from mental illness and to highlight the importance of providing the best support to families that we can.

1. Use slide E3 to explain the role of families:

<table>
<thead>
<tr>
<th>Role of Families</th>
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</thead>
<tbody>
<tr>
<td>When a patient is living in the community families often provide the majority of care and support that they need</td>
</tr>
<tr>
<td>Living with and caring for someone who suffers from mental illness can be very stressful and it is important that families receive support</td>
</tr>
<tr>
<td>Families often don’t understand the symptoms of mental illness and need information about the patients problems</td>
</tr>
<tr>
<td>Without help in managing their own stress and knowledge about the illness families may unintentionally behave in a way that increases stress for the patient and has a negative effect on the illness</td>
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2. Use questions to help participants to explore their understanding of the terms that are used, particularly those in italics. Ask participants what they think these terms mean. Good questions to use might be:

- Q1 - What might be stressful for families about having a relative who suffers from mental illness?
- Q2 - Why might it be important for family members to have an understanding of mental illness and how it affects the patient’s behaviour?
- Q3 - What types of problems might result if the relative does not have help to manage their own stress?
- Q4 - What do we mean by the family member unintentionally behaving in a way that increases stress for the patient?
- Q5 - Can anyone think of an example of something a family member might do with good intentions that could cause the patient stress.
Activity 3: Family member’s behaviour that may increase stress for the patient  50 minutes

Method
- Role play
- Large group discussion
- Presentation

1. Ask for five volunteers from the class, three men and two women. Once volunteers have been identified arrange their seats at the front of the room in clear view of other group members.

2. Tell the volunteers that you are going to describe a family to them and that each one of them will be given the role of a member of that family and you want them to behave ‘as if’ they think that person would do in real life. Case study E1 should be used for this exercise. Before reading the case study check that you have adequately explained the exercise and that everyone has understood what you said. The case study has been attached to this module plan and can be copied for participants to read as a handout if facilities for copying are available. Give the volunteers a role each as Sipho, Edith, Thabo, Charity or Simon. Make sure everyone knows ‘who they are’ for the role play.

3. Describe the following incident to everyone:

“Simon has been taking medication for 6 months now and he has stopped talking to himself and seems less agitated. However, he complains of having no energy, he sleeps for long periods of the day and does not take good care of his appearance or hygiene. Sipho returns from work to find Simon is still in bed at 4 o’clock in the afternoon. Sipho is angry because Edith did not get the boy up to do some chores around the home. Edith argues that she did not wish to disturb him because ‘he is ill and he needs his sleep’. Once Simon is out of bed Sipho decides that he should have a talk to Simon about how he would like him to change his behaviour and start taking more responsibility for his own life and help out more in the family home. The other family members are all present at this discussion.”

4. The objective of this exercise is to demonstrate how this situation, which is relatively common in families who have a mentally ill member, can be stressful for all concerned. Also it is likely that each family member will have their own ideas about how to resolve the problem and that this may cause conflict between them. Explain that you want everyone to act out the family discussion each behaving as they think their character would do in real life.
5. Allow the role play to continue for 10 – 15 minutes until the volunteers have had the opportunity to experience some of the emotions that this family might go through. Behaviours that should be observed for and highlighted include criticism of Simon and over-protectiveness. It is also worth considering what types of beliefs about Simon’s problems may underpin these behaviours by the family members.

6. Stop the role play after 15 minutes. First praise the volunteers for their efforts then ask each of them how they felt emotionally during the role play and what they were thinking about the situation and Simon’s behaviour. Start with the person playing Sipho, then Edith, followed by the Thabo and Charity and finally Simon. Be sure to ask Simon how the family members’ behaviour made him feel. Whilst they are explaining their thoughts and feelings write key phrases they say down on the flip chart or chalk board.

7. Summarise the exercise by reading back to the volunteers and the larger group some of the thoughts and feelings that the role players experienced. Highlight that such experiences are common in families who have a mentally ill member and may cause stress for all concerned.

8. Finally tell the group that for the remainder of the module we will be focussing on behaviours of family members that may be particularly stressful for the patient and considering how we support families to reduce this stress.

9. Using slides E4 and E5 explain about behaviours of family members that the patient may find particularly stressful. It should be emphasised however that these types of behaviours are NOT abnormal and usually come about because of concern for the patient combined with frustration from failed attempts to cope with the patients problems.

<table>
<thead>
<tr>
<th>Behaviour by family members that may increase stress for the patient (1)</th>
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<tbody>
<tr>
<td>• Critical comments (CC’s)</td>
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<td>- such as saying the patient is lazy, doesn’t try to help themselves or deliberately behaves badly to embarrass the family</td>
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<td>- sometimes the tone of a relatives voice may imply criticism rather than the content of what they say</td>
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<tr>
<td>• Critical comments usually occur because the family member cares about the patient but feels frustrated by their lack of progress or doesn’t recognise some of the behaviours as being part of the illness</td>
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*Slide E4*
Behaviour by family members that may increase stress for the patient (2)

- Over-protectiveness
  - treating the patient like a child
  - managing the patients affairs for them
  - doing as much as possible for the patient
  - seeing the patient as vulnerable and not wanting them to participate in normal activities for someone of their age
  - not allowing the patient space when they feel tense

- Like critical comments over-protectiveness generally occurs when the family care for the patient and want to help them as much as they can
Activity 4: Understanding the effects of family environments 15 minutes

Methods

- Presentation

1. Show slide E6 and explain to the group that within the higher chance model families are viewed as having the potential to cause secondary stress for the patient. However if we provide appropriate help and support to families they can be very supportive and reduce stress for the patient.

Give the group the opportunity to ask questions in case anything that you have said is not clear.

Understanding mental illness

\[
\begin{align*}
\text{Higher Chance} & \quad + \\
\text{Stress} & \quad = \\
\text{Symptoms of mental illness} & \quad \rightarrow \quad \text{More stress}
\end{align*}
\]

*Slide E6*
Activity 5: Behaviour by family members that may reduce stress for the patient  15 minutes

Methods

- Presentation
- Discussion

1. Ask the group what type of behaviour by family members might help to reduce stress for the patient. Encourage them to think of the answers themselves by asking questions. Some useful questions may be:

   Q1 - what helps you to reduce stress when you feel under pressure?
   Q2 - what would be helpful to you if you had a lot of problems to deal with?
   Q3 - if someone in your family was unhappy with your behaviour how would you like them to tell you about their dissatisfaction?

2. Explain the types of behaviours by family members that may help to reduce stress for the patient by going through the points on slide E7.

<table>
<thead>
<tr>
<th>Behaviour by family members that may reduce stress for the patient</th>
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<tbody>
<tr>
<td>• Communicating in a clear and direct way with the patient but avoiding making critical comments or using a critical tone of voice</td>
</tr>
<tr>
<td>• Allowing the patient to take some responsibility for their own affairs</td>
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<tr>
<td>• Giving the patient some space when they are feeling tense and need to be on their own</td>
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<tr>
<td>• Remaining calm and discussing problems and potential solutions in a productive way with the patient and other family members</td>
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*Slide E7*
Activity 6: Providing support to families  50 minutes

Methods

- Presentation
- Discussion
- Role play
- Modelling skills used when supporting families

1. Go through slide E8 and explain that you are going to undertake a short exercise to help participants practice giving information about the illness.

<table>
<thead>
<tr>
<th>Providing support to Families of people with Mental Illness (1)</th>
</tr>
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<tbody>
<tr>
<td>Help families to:</td>
</tr>
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</tr>
<tr>
<td>2. Understand the importance of not being critical or over-protective</td>
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**Slide E8**

2. Ask for a volunteer from the group to play the role of Sipho in case study E1. Using the role play script E2 provided with this module the teacher should play the role of a worker who is providing support to the family. The role play is to demonstrate how Sipho can be helped to understand that Simon is suffering from an illness that can be made worse by stress. One source of stress is if Sipho is critical of Simon’s behaviour. In the role play Sipho is advised that if he is unhappy with Simon’s behaviour it is better to express his opinion clearly and calmly and ask Simon what he thinks would help to solve the problem.

3. Once the role play is finished ask the larger group to say what they liked about how the information was given to Sipho and anything that might have been done differently.

4. Ask participants to divide in to groups of three, tell them for one of them to play the role of one of Simon’s family and one the role of a support worker, the third person should observe the role play. Their task is to explain to the relative about the effect of stress on Simon’s illness and to educate the family that one potential source of stress might be to do too much for Simon and not allow him to take some responsibility for his own life.
5. Once the role play has finished the observer in each small group of three people should provide feedback to the person playing the role of the worker about what they liked about how they gave information and what might have been done differently.

6. This role play should be repeated three times with participants changing roles each time until everyone has had a chance to play the role of the worker.

7. Go through slide E9 and use questions to help participants explore how they could support families and help them to reduce their own stress.

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**Providing support to Families of people with Mental Illness (2)**

- Help families to:
  1. Find ways of reducing their own stress
  2. Support the patient in their recovery from the illness whilst recognising this may take time.
  3. Maintain some of their own interests and do not devote their life to the patient

*Slide E9*
Activity 7:  What Have We Learnt?  10 minutes

Method
• Large Group Discussion

1. Ask participants to say what they have learned from the whole of module E.

2. Do not discuss the individual contributions at this stage. Allow individual participants to say whatever they wish about the module.

3. Write each contribution down on a flipchart or chalkboard.

4. Summarise the groups suggestions at the end. Feedback what the group have said and end on a positive note.

5. Take a well earned break.
Case study E1: Sipho and family

Sipho is a 46 year old married man who lives with his wife and three children. Sipho is employed as a dock worker, he is a very proud man who works long hours and believes that work is very important to a person’s sense of pride in who they are.

Edith is 44 years old she is Sipho’s wife and mother of their three children. Since marrying Sipho at the age of 19 years her role has been to raise her children and care for the family home. Edith’s is fiercely proud of her children and her life revolves round them.

Thabo is 23 years old and is the eldest of the three children, he is a hard working boy who has recently graduated from University and has started upon a promising career as an engineer. He is a confident boy who has many friends and although he still lives at home his ambition is to live and work overseas in the USA or Australia.

Charity is 21 years old and is the only girl in the family. Although very clever at school she did not continue her education and has a job in a local shop. Charity has a steady boyfriend who she intends to marry when they can afford to buy a home of their own.

Simon is 19 years old and is the youngest child, his parents describe him as a bright and intelligent boy who performed well at school and they had high hopes for his future. Two years ago Simon started to spend increasing amounts of time on his own, sometimes he could be heard talking to himself and others times his conversation made no sense to his family. Eventually following an incident when he nearly drowned because he claimed he ‘could walk on water’ he was seen by a doctor and started on treatment for severe mental illness.
Incident

Simon has been taking medication for 6 months now and he has stopped talking to himself and seems less agitated. However, he complains of having no energy, he sleeps for long periods of the day and does not take good care of his appearance and hygiene. Sipho returns from work to find Simon is still in bed at 4 o’clock in the afternoon. Sipho is angry because Edith did not get the boy up to do some chores around the home. Edith argues that she did not wish to disturb him because ‘he is ill and he needs his sleep’. Once Simon is out of bed Sipho decides that he should have a talk to Simon about how he would like him to change his behaviour and start taking more responsibility for his own life and help out more in the family home. The other family members are all present at this discussion.
Module E

Sipho and Teacher: Role Play Script E2

Teacher A  Sipho – it sounds as though things have been very stressful for all of you over the last few days.

Sipho  Well – it’s just the same – Simon stays in bed all the time – doesn’t help out with the chores – doesn’t do anything at all.

Teacher A  It seems as though Simon’s levels of activity are causing you a lot of distress.

Sipho  Yes – not just me – Edith is upset but she won’t say anything to him. She’s tells me he’s ill – he needs to rest – but he needs to get up – help out at home and get a job!

Teacher A  So Edith finds it stressful too. I was talking to Simon last week and he was saying that he finds it frustrating that he spends a lot of time in bed too.

Sipho  Well why doesn’t he get up and get out of bed then. Why doesn’t he do anything?

Teacher A  I think it’s likely that Edith is right when she says that it’s part of the illness.

It might seem strange but it’s very common for people with mental health problems like Simon to be inactive, to withdraw from people and activity and spend long periods of time doing very little.

These things are called the negative symptoms – they are things we would usually expect people to do but when they are unwell they don’t.

Sipho  But I thought he was being lazy.

Teacher A  I can see why you would think that it was laziness and it’s not uncommon for relatives to think this when they see their children not doing very much.

Obviously in some people not doing very much is a sign of laziness but in people with severe mental illness it is a symptom of the illness which often causes stress for the person with the illness and the people looking after them.
Sipho: So – he’s not being lazy – it’s part of the illness.

Teacher A: Yes – what about before Simon became ill – was he a lazy child?

Sipho: No – in fact he was very hard working at school. We had such high hopes for him.

Teacher A: It seems that Simon becoming unwell as had a big impact upon you all and you’re worried now about his future. It may be helpful to know though that there are ways we can help Simon to increase his activity levels.

While Simon may always have problems with his mental health – there are ways we can help him and you to manage the stress and provide rehabilitation.

Sipho: What sort of things can we do to help? I do find it so frustrating. I know it isn’t helpful to shout at him but I can’t help it sometimes.

Teacher A: I appreciate it is difficult at times - perhaps understanding that his staying in bed is part of the illness rather than his being lazy will help. It can also be helpful to explain to Simon in a clear calm way – that you are unhappy with aspects of his behaviour and ask Simon what he thinks might be helpful. Often people with severe mental illness have lots of ideas about what would help them get up and do more.

Sipho: So it would be helpful to let him know I’d like him to do more around the house but try not to be critical and let him make some suggestions about what we can do to help?

Teacher A: Yes – that’s it. Hopefully that will reduce stress for all of you and be more helpful for Simon in the future. It can often be helpful to start with small tasks which Simon enjoys and work towards bigger tasks with the full support of his families. I think Simon would appreciate us working with him to find some activities he’d like to do.
Module E:
Helping Families Cope with Mental Health Problems
Aims of the Module

• Consider the role of families in caring for mentally ill people in the community
• Discuss the importance of families having an understanding of mental illness and the patient’s behaviour
• Highlight behaviours of family members that may increase stress for the patient
• Describe helpful behaviours of family members that reduce stress for the patient
Role of Families

- When a patient is living in the community families often provide the majority of care and support that they need.
- Living with and caring for someone who suffers from mental illness can be very stressful and it is important that families receive support.
- Families often don’t understand the symptoms of mental illness and need information about the patients problems.
- Without help in managing their own stress and knowledge about the illness families may unintentionally increase stress for the patient and has a negative effect on the illness.
Behaviour by family members that may increase stress for the patient (1)

- Critical comments (CC’s)
  - such as saying the patient is lazy, doesn’t try to help themselves or deliberately behaves badly to embarrass the family
  - sometimes the tone of a relatives voice may imply criticism rather than the content of what they say

- **Critical comments usually occur because the family member cares about the patient but feels frustrated by their lack of progress or doesn’t recognise some of their behaviours as being part of the illness**
Behaviour by family members that may increase stress for the patient (2)

• Over-protectiveness
  – treating the patient like a child
  – managing the patients affairs for them
  – doing as much as possible for the patient
  – seeing the patient as vulnerable and not wanting them to participate in normal activities for someone of their age
  – not allowing the patient space when they are feeling tense

• Like critical comments, over-protectiveness generally occurs because the family care for the patient and want to help them as much as they can
Understanding mental illness

Higher Chance

+ Stress

= Symptoms of More mental illness stress

= More stress
Behaviour by family members that may reduce stress for the patient

• Communicating in a clear and direct way with the patient but avoiding making critical comments or using a critical tone of voice

• Allowing the patient to take some responsibility for their own affairs

• Giving the patient *space* when they are feeling tense and need to be on their own

• Remaining calm and discussing problems and potential solutions in a productive way with the patient and other family members
Providing support to Families of people with Mental Illness (1)

• Help families to:

1. Have a better understanding of the illness and its effects on the patients behaviour

2. Understand the importance of not being critical or over-protective
Providing support to Families of people with Mental Illness (2)

• Help families to:

1. Find ways of reducing their own stress

2. Support the patient in their recovery from the illness whilst recognising this may take time

3. Maintain some of their own interests and do not devote their life to the patient