

# Interview with patient

## General

1. Age: ...
2. Gender:
  - Female
  - Male
  - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
  - No
  - Yes
    - Christian
    - Jewish
    - Muslim
    - Hindu
    - Buddhist
    - Other, ...
6. Relationship status: ...
7. Children:
  - No
  - Yes, ... children
8. Living situation:
  - a. Single
  - b. Partner
  - c. Married
9. Educational level:
  - Primary (age 12)
  - Secondary (high school, age 17)
  - Tertiary
10. Employment: ...
11. Monthly income:
  - 0-2000 SRD
  - 2000-5000 SRD
  - 5000-10000 SRD
  - More than 10000 SRD

## Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that you were having difficulties and how you were dealing with them. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.

If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?

Then we would like to get started.

## Initial illness narrative

1. People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would you describe the problem you had?
  - a. What troubled you the most about your problem?
2. At a certain point, you may have noticed that something was different from normal. When did you experience changes or difficulties for the first time?
  - a. Can you describe the changes or difficulties you first noticed?
  - b. Did you notice any changes or difficulties yourself, or did someone else notice this?
  - c. Did someone else notice at all that you behave differently or had difficulties?
  - d. At that time, what did you think of of the changes and difficulties?
    - i. Did you understand the seriousness?
    - ii. Did you understand that you were unwell?
3. I would like to know more about your experience with your first changes and difficulties. Can you think of anything that changed in your life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
  - a. Did you use drugs for pleasure at that time?
  - b. Did you receive any medication prescribed by a doctor at that time?

**Prototype narrative**

1. In the past, have you ever had a health problem that you consider similar to your current health problem?
2. Did a person in your family ever experience a health problem similar to yours?

**Explanatory model narrative**

1. A lot of people have their own thoughts about their health problem. I would like to know something about what you thought at that moment.
  - a. What did you think was happening to you?
  - b. What did you think was the cause of your health problem?
2. Family members may also have their own thoughts about someone's health problem. I would like to know what they thought of yours at that moment.
  - a. What do others in your family, friends, or in your community think was causing your problem?

**Past help seeking**

1. People all react differently to problems like yours. What did you first do when you realised you had a health problem?
2. When did you first try and find help? What made you decide to do so?
3. Did anything prevent you from getting the help you need?
4. Often, people look for help from many different sources, including different kinds of doctors, helpers, or healers. In the past, what kinds of treatment, help, advice, or healing have you sought for your health problem?
  - a. What types of treatments were helpful?
  - b. What types of treatments were not helpful?
  - c. [If not mentioned traditional healing]. A lot of people with health problems similar to yours go to a traditional healer.
    - i. Did you also go to a traditional healer?
5. Who decided to contact professional medical help? E.g. was it you or a family member who reached out.
6. Could you tell us more about how you felt when you talked with the medical professional?

**Accessibility to care**

1. I would like to ask a few questions about the nearest health clinic.
  - a. How far is it from you?
  - b. How long does it take for you to get there?
  - c. How do you get there?
  - d. Are there any reasons you can't get there? Possibilities could be that you can't leave the house, no time due to work, family does not agree or the cost.

2. Sometimes doctors and patients misunderstand each other because they come from different backgrounds or have different expectations.
  - a. Have you ever been concerned about this?
  - b. Did you face this problem when seeking help from a doctor?
3. What do you think of medical services? Do you have the feeling they could help you with your health problem?

### **Role of cultural identity**

1. People have different backgrounds or identity's. Me for example, value my family and my place of birth very much. How is that in your case?
  - a. For you, what are the most important aspects of your background or identity?
2. Sometimes also, being from a particular background or having a certain identity can cause problems. In my case, being from a certain part in The Netherlands, stereotypes can sometimes give people wrong ideas about who I am.
  - a. Are there any aspects of your background or identity that are causing other concerns or difficulties for you?

### **Stigma**

1. Does your family have an opinion regarding seeking medical treatment?
  - a. Is this opinion influenced by their culture?
2. A health problem like yours can be misunderstood by many people without knowledge about psychosis for example.
  - a. Do you feel that people treat or look at you differently since you've had mental health problems? By people we mean for example your religious community, friends or family?

### **Costs**

1. How do you pay for your medical treatment?
2. Did you ever think twice about contacting medical services because of the costs?
3. If you have insurance, does it cover all costs regarding your illness?

### **Social support**

1. Speaking about health problems may give relief for some people. It is sometimes nice to get something off your chest. Is this for you also the case? Or don't you share anything with anybody?
  - a. Did you share your problems with your friends or family?
  - b. Did your family or friends suggested or offered you any kind of help for your health problem?
  - c. Are there any kinds of support that make your problem better, such as support from family, friends, or others?

**Other**

1. ...
2. ...

*For example, the communities you belong to, the languages you speak, where you or your family are from, your race or ethnic background, your gender or sexual orientation, or your faith or religion.*

# Interview with family

## General

1. Age: ...
2. Gender:
  - Female
  - Male
  - Other, ...
3. Ethnicity: ...
4. Place of birth: ...
5. Religion:
  - No
  - Yes
    - Christian
    - Jewish
    - Muslim
    - Hindu
    - Buddhist
    - Other, ...
6. Relationship status: ...
7. How are you related to the patient?: ...

## Introduction

Firstly, we would like to thank you for being here and for being part of this research. Before we start we would like to introduce ourselves. Our names are [Menno de Leeuw] [Atousa van Beek] [Mia Poplawska] [Lise Kerkvliet] and we are medical students from the Netherlands. For our studies we have set up this research here. For our research we will be looking into experiences and difficulties encountered from people who have had or know someone with psychosis, such as yourself. Therefore, we are very glad that you are willing to share your story with us.

We would like to understand the problems or difficulties that you experienced in the past. We want to know your experience. We will ask some questions about the period that your family member was having difficulties and what your view on this was. Just as a reminder we would like to let you know that this interview will be recorded. Only people involved in the study such as ourselves will be able to access these recordings.

Please remember there are no right or wrong answers, and that everything you say will be confidential and treated anonymously. You do not have to answer any questions you are not comfortable with.

If at any point something we say or ask is unclear, do not hesitate to ask a question about it.

Do you have any questions for us?

Then we would like to get started.

### Initial illness narrative

1. Can you describe (*name of patient*) before they became ill?
2. At a certain point, you may have noticed that something was different from normal. When did you notice that (*name of patient*) changed or had some difficulties for the first time?
  - a. Can you describe the changes or difficulties you first noticed?
  - b. At that time, what did you think of of the changes and difficulties?
    - i. Did you understand the seriousness?
    - ii. Did you understand that they were unwell?
3. I would like to know more about the period when you first noticed changes in (*name of patient*). Can you think of anything that changed in their life at that time? Examples can be: a lot of stress, loss of a loved one or a break-up.
  - a. Did they use drugs for pleasure at that time?
  - b. Did they receive any medication prescribed by a doctor at that time?
4. Can you describe what happened in the period after (*name of patient*) was diagnosed?
5. How were you involved when (*name of patient*) was unwell or had difficulties? Was there for example something you could do to help him/her?

### Prototype narrative

1. Did a person in your family ever experience a health problem similar to (*name of patient*)?

### Explanatory model narrative

1. A lot of people have their own thoughts about the reasons for a health problem. I would like to know something about what you thought about your family member at that moment.
  - a. What did you think was happening to him/her?
  - b. What did you think was the cause of his/her health problem?
2. We would like to know about your experience after you found out (*name of patient*) was ill.
  - a. What effect did the diagnosis have on you?
  - b. How did you cope with it?

### Past help seeking

1. People all react differently when a family member becomes ill. What did you first do when you realised they had a health problem?
2. Did you talk to him/her about trying to find help? Can you explain how this went?

### Care

1. Did (*name of patient*) attend the first doctor appointments or didn't they want to talk to a medical professional?

2. What did you think of the first medical professionals that helped your family member?
3. What do you think of medical services? Do you have the feeling they could help with his/her health problem?

**Costs**

1. Were you involved in paying (*name of patient*) his/her medical treatment?
2. Did you ever think twice about contacting medical services for (*name of patient*) because of the costs?

**Other**

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