

Focus group 1

Introduction by saying:

- Welcome
- Aim of the focus group conversation is to explore experiences of living with a person with a pituitary disease and the impact on their lives
- All conversations are confidential
- Conversations will be audiotaped and typed-out verbatim
- Please avoid talking over each other
- Avoid non-verbal communication (i.e., nodding), since this cannot be audiotaped
- Ask everyone to introduce themselves and say briefly something about work, family composition, hobbies, when was your partner diagnosed with the pituitary condition

Starting question:

- What do you encounter in daily life related to the pituitary condition of your partner?

The discussion will be continued by using open-questions sometimes followed by closed questions that act as prompts for discussion

Finishing conversation:

- Ask whether participants want to add a final remark to the conversation.
- Saying that the next focus group meeting will be within 2 weeks at a certain time/date.

Focus group 2

Introduction by saying:

- Welcome
- Aim of the present focus group meeting is to have a more in-depth conversation based on issues raised during the previous meeting
- All conversations are confidential
- Conversations will be audiotaped and typed-out verbatim
- Please avoid talking over each other
- Avoid non-verbal communication (i.e., nodding), since this cannot be audiotaped

The discussion during the second focus group meeting was held by using a topic list (below) based on the first focus group meeting. The discussion was continued by using open-questions sometimes followed by closed questions that act as prompts for discussion.

Topic list

Mood

How does the pituitary condition of your partner affect your mood?

- Anxiety?
- Depressive symptoms?

Emotions

- Anger?
- Guilt?
- Frustration?
- Tension?
- Loneliness?
- Insecurity?
- Sadness?

How do you cope with emotions/tension?

Stress

How do you experience stress?

How do you cope with stress?

Coping

Which adaptation do you need to make in your daily life, as a result of the pituitary condition of your partner?

- Problems accepting?
- Crossing own limits

Relationship

When the physical appearance of your partner has changed, how does this affect you?

When your partner has physical complaints, how does this affect you?

When the personality of your partner has changed, how does this affect you?

When your partner suffers from mood changes, how does this affect you?

When your partner suffers from cognitive complaints, how does this affect you?

When your partner suffers from sleep problems, how does this affect you?

Is the balance in your relationship influenced by the pituitary condition?

When this is the case, how is it affected?

- Skewed relationship?

Do you have the feeling that you need to protect your partner? When this is the case, how does this affect you?

Do you feel supported by your partner?

Is the communication between you and your partner influenced as a result of the pituitary condition? When this is the case, how is it affected?

Do you encounter problems with a desire to have children?

Has sexuality/intimacy changed in your relationship, when yes how does this affect you?

Family

Does the pituitary condition of your partner influence your family? When this is the case how does it affect your family?

Do you feel supported by your family?

Social functioning

Do you feel supported by your social network?

Is the communication between you and your social network influenced as a result of the pituitary condition? When this is the case, how is it affected?

How does the pituitary condition of your partner affect your social life?

How does the pituitary condition of your partner affect your social network?

Employment

How does the pituitary condition of your partners affect your financial situation?

How does the pituitary condition of your partner affect your work?

Unmet needs (final questions):

- Given all of this, what would you prefer to have known / to have had after receiving the diagnosis of your ill partner?
- What is your advice for someone who just received the diagnosis?

Finishing conversation:

Thank participants for their contribution