

Online Supplementary Material

Gallacher K, May CR, Montori VM, Mair FS. Understanding patients' experiences of treatment burden in chronic heart failure using Normalization Process Theory. *Ann Fam Med.* 2011;9(3):235-243.

<http://www.annfammed.org/cgi/content/full/9/3/235/DC1>

Supplemental Appendix 1. Interview Schedule: Patients' Perceptions

Background Information for the Interviewer

In situations where there is a lack of knowledge, questions will be posed in a manner which takes account of such a limitation.

The interview will be semi-structured in format and will allow the patient to talk at length about their views about their illness and treatment.

Introduction Procedure with Patients

1. Give complete name.
2. Identify self as a researcher.
3. State that the doctors at the surgery know about the study.
4. Give short explanation of the purpose of the study:

"I would like you to help me understand what you feel about having this condition which the doctor has given you _____ medicine to treat. I am not a doctor nor am I medically trained. I really just want to find out your views on how you feel about your condition and the medicines you are taking. Please feel assured that no one will be able to identify you from what you say when talking to me and everything you tell me will be treated in the strictest confidence."

"We think it is important to know not only how the illness affects your body, but also if you think it affects your every day life, and if so in what ways?"

"It is very important that you know we are only interested in understanding about this particular illness for which the doctor prescribes _____ for you to take. If at any time you want to stop, or have a break, or find answering distressing at any time, please feel free to let me know."

"I usually record the interviews, so it is possible to write notes from it and then wipe the tape. However, if you prefer I can make notes instead."

5. Consent form.

PATIENT PROFILE

Name:

- Age: 18-35 years ()
 36-49 years ()
 50-64 years ()
 65-79 years ()
 80+ years ()

Gender: Male () Female ()

Length of time registered with current practice:

- | | |
|-------------------|-----|
| Less than 5 years | () |
| 6 to 15 years | () |
| 16 to 24 years | () |
| 25+ years | () |

Have you been in hospital for the condition you are taking _____ to treat

- | | |
|-----|-----|
| Yes | () |
| No | () |

Have you seen a cardiologist/heart specialist regarding the condition you are taking
_____?

- | | |
|-----|-----|
| Yes | () |
| No | () |

Marital Status:

- | | |
|--------------------|-----|
| Single | () |
| Married | () |
| Separated/Divorced | () |
| Widowed | () |

Have you any children?

- | | |
|-----|-----|
| Yes | () |
| No | () |

Can I ask how many?

- | | |
|----|-----|
| 1 | () |
| 2 | () |
| 3 | () |
| 4 | () |
| 5+ | () |

Date and Time of Interview:

INTERVIEW QUESTIONS

Application of a Diagnosis/Label

It is important to explore the circumstances in which the patient became aware that s/he had a health problem related to their chest or their breathing.

1. Do you recall what was wrong, what was the problem you had when you were started on
_____?

NB: Remember to probe, even when patient responds "no."

Breathing

- 2a. Have you ever had problems with your breathing? If no, go to Question 3a. (For example, feeling short of breath when you are exerting yourself or at night)
- 2b. Can you tell me about this? Describe what it is like and when it tends to happen? (ie, do they relate it to the condition?)
- 2c. When did you become aware or in what circumstances did you know that you had problems with your chest/breathing?
- 2d. Have you been told anything about this problem by a doctor? What?

Ankle Swelling

- 3a. Have you ever had problems with your ankles swelling? If no, go to Question 4a.
- 3b. Can you tell me about this? (ie, do they relate it to the condition?)
- 3c. Have you been told anything about this problem by a doctor? What?

Fatigue/Tiredness

- 4a. Do you have problems with feeling tired? If no, go to Question 5a.
- 4b. If yes, can you tell me about this? (ie, do they relate it to the condition?)
- 4c. Have you been told anything about this problem by a doctor? What?

Label Applied to Condition

- 5a. Has there been a name given to your condition? If no, go to Question 6a. If yes, what is the name you have been given?
Prompts: GP/family doctor
Hospital doctor
Nurse
- 5b. Was this name of your condition given to you by a medically qualified person? Who?
Prompts: GP/family doctors' surgery
In hospital
- 5c. Where was this name for your condition given to you?
Prompts: GP/family doctors' surgery
In hospital
- 5d. What do you understand by the name given to your condition?

Health Beliefs

This area of the questioning addresses the model that patient has of the condition. The experience of heart failure may be located within an entirely *medical model* where it is regarded as an illness. Conversely, it may be viewed as having *psychosocial aspects* and not having a clear definition which can be applied to it by the patient. Understanding this is important when attempting to explore apparent *adherence* or apparent *nonadherence* with either *medication* or *advice*.

- 6a. Do you regard yourself as having an illness?
- 6b. If yes, could you explain to me what you mean by this reply?
If no, could you explain to me what you mean by this reply?
- 6c. How do you feel you cope with this particular illness/problem (if patient said no to illness)?
Prompts: Worry you
Get you down

Meaning of the Patient Role

After establishing the patient's understanding of the diagnosis/label of heart failure and his or her health beliefs, there is a need to:

- i) *explore the part heart failure plays in the patients' every day existence.* It is hoped that this response could be categorized in terms of a fraction or percentage.

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- 7a. Is it possible to tell me roughly how many times:
a day?
a week?
a month?
a year?
you are aware that you are affected by this condition that you have been given the
medication for?

7b. Please can you describe how it affects you?

7c. When does it tend to affect you?

Prompts: In bed
When going upstairs
When rushing

ii) to gain understanding of a patient's perceptions of heart failure

This relates to the "social aspects" of the medical condition of heart failure. It relates to the interface between the medical and social aspects of the condition.

8a. Are you working at present? If no, go to Question 8b.

What happens at work when you have symptoms of this condition?
Does having this condition affect your life at work?
Do you have to alter your routine at work?
Please describe how your having such a condition is viewed by a) your employer and b) your work colleagues.

8b. Does having this condition affect your life at home?

Does having this condition affect your ability to perform daily chores?

Prompts: Cleaning the house
Going shopping

Do you have to alter your routine at home because of this illness?

Please describe how your having such a condition is viewed by

- a) yourself,
- b) your family, and
- c) your friends.

8c. Does having this condition affect your social life/leisure activities?

Prompts: Going out with friends
Performing certain activities

Do you have to alter your social life/leisure activities because of this illness?

8d. Does this condition prevent you from doing anything you wish to do?

Prompts: For example, things you did immediately prior to this illness

8e. What are your expectations for the future in view of the condition you are taking
medications to treat?

iii) to explore whether the participant is an active or a passive patient

This will assist to establish the relationship between this perception to adherence/non adherence.

9a. We've talked about how you cope when you have symptoms/this illness, could you now tell me whether or not:

- i) you have asked/do ask the doctor *questions* about your condition/illness? If no, go to iii)

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- If yes, ii) Did/do the doctor answer the question (s) you have asked?
iii) You have asked/do ask the doctor to *explain* about your condition/illness? If no, go to Question 9b.
If yes, iv) did/do the doctor provide an satisfactory explanation?

9b. Do you feel able to ask the doctor for advice or help about your condition:

Prompts: Symptoms
Treatment

Have you sought information /advice about your condition from anyone or anywhere else?

Prompts: Magazines
Health information leaflets
Family/friends/others with the same condition

- 9c. i) Has the doctor offered you any choices about your treatment?
ii) How involved do you feel you are in decision about your treatment?

9d. Do you know of any signs or symptoms to look out for that would suggest you should seek medical advice?

9e. Please describe any advice you've received relating to your condition?

Prompts: Lifestyle changes – diet; exercise

9f. Is there any information you would like to receive about your condition/illness which you have not received?

Medications

This category is included to ascertain the rationality of nonadherence from the patients' perspective. Questions should concern the patients attitudes to the process of taking medication—maybe *using some of the views they expressed on the more general issue of health beliefs*.

This section requires a degree of judgment to its conduct due to the delicate nature of the area under exploration.

Reemphasize to the patient that the information offered is confidential and anonymous.

- 10a. i) How do you find taking the medicine (name) the doctor has prescribed for you?
ii) Are you taking medications for any other illness (es)?
iii) Do you find it difficult to remember how or when to take your medicine?
iv) Have you learned any ways to help you to remember how or when to take them?

If talked about other illness(es), restate at this point that you are interested in the condition that the doctor has given them _____ (name of medications) to treat.

- 10b. i) Do you mind taking the medicines the doctor has prescribed for you?
ii) Do they bother you in any way?
iii) Are you worried they might cause side effects?

If no, go to Question 10c.

- If yes, Please describe these for me.
iv) Have you ever discussed this with your doctor?

- If yes, Please can you tell me about it?
If no, Please can you tell me why you haven't discussed it with your doctor?

- 10c. i) Can you tell me what medicine(s) you have taken so far today?

Prompts: Names of diuretics and ACE inhibitors

- ii) Do you think it is important to take the medicine a doctor prescribes for you?

- If yes, ask patient to expand upon response
If no, ask patient to expand upon response

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- iii) What effect do the medications have upon your condition?
Prompts: Feel better
 Feel worse
- iv) Please describe any worries you have about the medicine that is prescribed for you?
- 10d. i) Do you have to pay for any of your prescriptions? If no, go to Question 10e.
If yes, ii) Have you ever been unable to get your medicines because of cost?
If yes, iii) How often has this happened?
iv) Have you had any problems when you've stopped taking the medicines?
- 10e. How do you get your medications?
Prompts: Patient collects them from the chemist themselves.
 Someone collects them on behalf of the patient.
 The pharmacist delivers them to the patient's home.
- 10f. i) Are there any other ways in which health professionals could offer you more help with your condition?
Prompts: Doctors
 Nurses
 Etc
- ii) Is there any other nonmedical help which you think might be of benefit to the way you experience this condition/illness?
Prompts: Being in contact with other people with the same condition
 Having a telephone helpline
- iii) Do you belong to any support group that has people with the same or similar condition as you?

Close of Interview

I have asked all the questions I wanted to ask you. Are there any issues you would like to mention which I haven't covered?

Thank you, just to say once again that all you have told me today is confidential and completely anonymous.

ACE = angiotensin-converting enzyme; GP = general practitioner.