UMC Utrecht

COPD-GRIP intervention

University Medical Center Utrecht

Introduction

COPD patients are confronted with functional limitations in daily life. They are often short of breath, they cough a great deal and they experience reduced muscular strength. They may also experience fatigue and feel afraid and powerless. COPD stands for Chronic Obstructive Pulmonary Disease. This disease causes narrowing of the airways as a result of inflammation and, in severe cases, the airways are damaged. Managing and living with COPD is highly demanding for patients.

Medication and lifestyle changes can reduce symptoms and can have a positive effect on the course of COPD.
Some patients are able to remain very active and adhere to the treatment protocols and lifestyle changes. They experience fewer symptoms, function better and hospitalisations are required less frequently. Others do not succeed, or do not succeed to an adequate degree.
Therefore, it is important to highlight self-management and to support this within COPD treatment plans. Existing programmes do not devote enough attention to behaviours and behavioural changes.

In order to bring about behavioural change, it is important to gain an insight into patients' attitudes towards COPD and its treatment. These attitudes are referred to as illness perceptions. One patient will have an appropriate and positive illness perception, while another will have a less positive view of COPD. Research has shown us that people with positive and appropriate perceptions function better in daily life and experience less of a disease burden.

The COPD-GRIP intervention has been developed to gain an insight into patients' attitudes and perceptions and to change these where necessary. It offers an opportunity for improved self-management and reduced disease burden.
The development of this intervention is based on the MRC model of intervention development (Craig et al 2008; Craig et al 2013).

The content is based on the Common Sense Model (Leventhal et al 2003) and various studies on illness perceptions (Broadbent et al 2009; Cameron et al 2005; Davies et al 2007; Jansen et al 2009; Petrie et al 2002; Weldam et al 2013). The intervention provides an essential contribution to innovations in COPD care.

UMC Utrecht
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Intervention structure

The COPD-GRIP intervention (COPD Guidance, Research on an Illness Perception Intervention) has been developed for practice nurses in primary care, respiratory nurses and other primary care providers.

The COPD-GRIP intervention is described in this booklet. It has an equivalent structure for all patients. The specific content is individualized.

The intervention consists of three face-to face consultations of approximately half an hour, over a period of six weeks.

The objective of the first consultation (Understanding the patient's illness perceptions) is to gain an insight into the patient's attitude, perceptions and believes towards COPD. The purpose and the structure is described and the patient is asked whether he/she agrees with this. The B-IPQ questionnaire is completed and the answers are discussed. This provides an insight into the patient's perception of COPD.

In the next consultation (Identifying the link between illness perceptions and behaviour), the link between illness perceptions and behaviour is identified. The nurse makes the patient aware that perceptions of COPD can influence daily functioning. The nurse discusses with the patient which perceptions can be changed and how they can do so. On that basis, a personal care plan is created, with both short and long-term action points.

In the final consultation (Evaluation and discussion of the personal care plan), the nurse and patient assess whether the plan has been successful and what new action points are necessary for the future.

Guide

The B-IPQ questionnaire forms the basis for this intervention. These questions are highlighted in red.

Every question includes the following options for selection:
o The patient's perception is appropriate/realistic.
o This section requires further attention: carry over to the 2nd consultation.

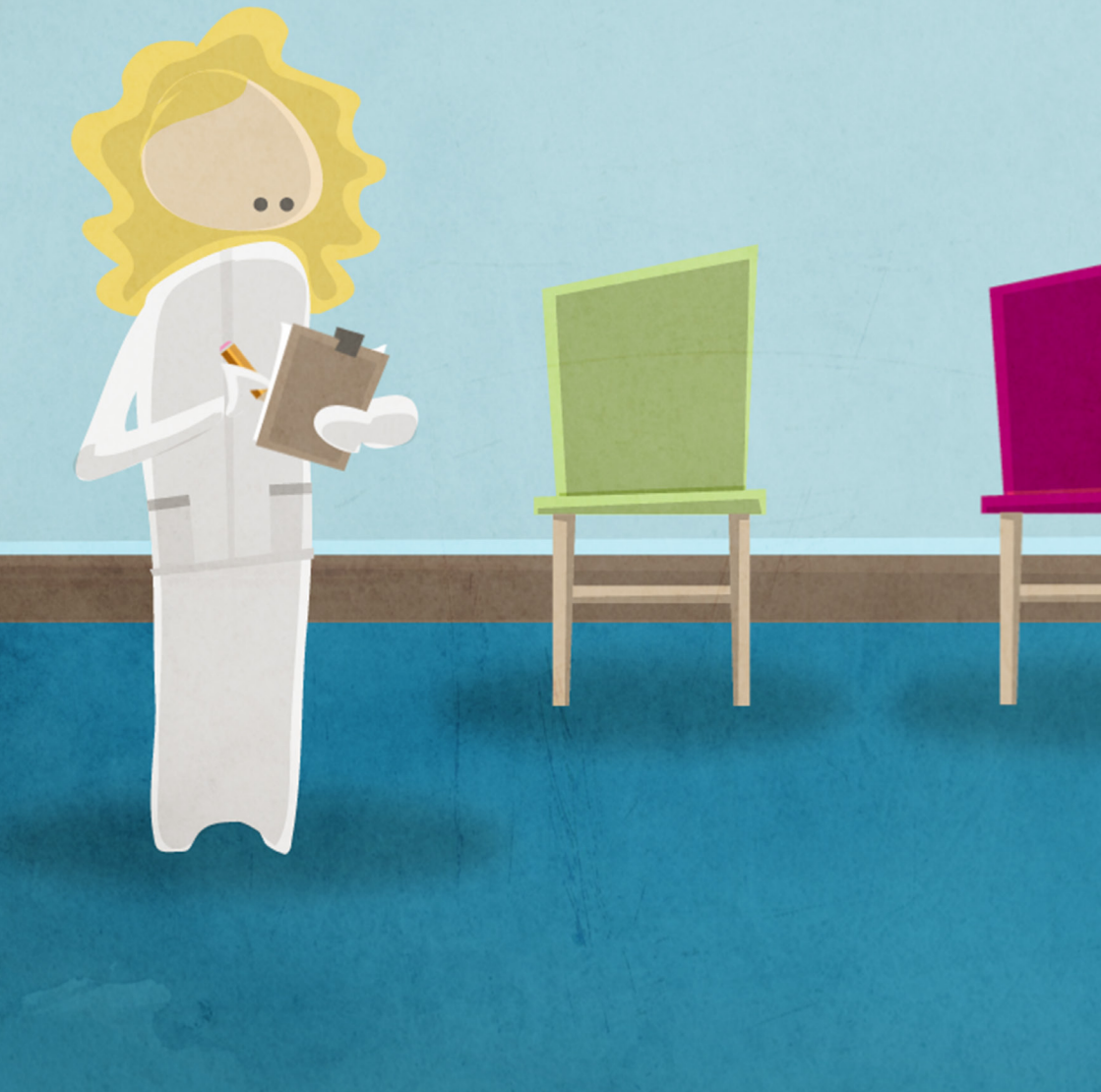
These points can be ticked. This highlights those areas that require further attention.

The suggested scripts that appear in coloured fields are intended as aids for the consultations. The nurse may apply his/her own interpretation.

By way of explanation, you could say:

"The aim of this consultation is to discuss with you what it is like to live with COPD and to assist you in making choices. It is not the intention that you do what I want, but rather that I offer advice that suits your lifestyle."

Consultation 1: Understanding the patient's illness perceptions



Consultation 1: Understanding the patient's illness perceptions

Step 1: Explain the purpose and the structure of this consultation

"The aim of this consultation is to discuss with you what it is like to live with COPD and to assist you in making choices. It is not the intention that you do what I want, but rather that I offer advice that suits your lifestyle."

"I would like to do this by asking you a few questions about your experience with COPD thus far. Then we can have a look together at what you need in order to manage living with COPD as well as possible."

Step 2: Indicate that you know living with COPD can be difficult.

"I know it can be difficult living with COPD, and I can imagine it up to a point, but I would like to hear what it is like for you. So, I would like to go through the answers to the questionnaire with you."

Step 3: Discuss the answers of the B-IPQ

You discuss the answers to each question on the B-IPQ with the patient. If discussion proves difficult, you can use the following examples:

"Discussing the answers with you gives me a good idea of your perception of COPD."
"Each answer is equally important, there are no incorrect answers, your personal answer is what matters."

"I would like to know why you gave these specific scores."
"How do you yourself feel about the score?"

1. How much does your COPD affect your life?

0: no affect at all

10: severely affects my life

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

"Can you explain how COPD impacts your life?"
"Can you tell me what it means to you to live with COPD?"

2. How long do you think your COPD will continue?

0: a very short time

10: forever

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

3. How much control do you feel you have over your COPD?

0: absolutely no control

10: extreme amount of control

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

4. How much do you think your treatment can help your COPD?

0: not at all

10: extremely helpful

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

5. How much do you experience symptoms from your COPD?

0: No symptoms at all

10: Many severe symptoms

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

6. How concerned are you about your COPD?

0: Not at all concerned

10: Extremely concerned

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

7. How well do you feel you understand your COPD?

0: I do not understand at all

10: I understand my disease very clearly

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

8. How much does your COPD affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

0: not at all affected emotionally

10: extremely affected emotionally

If there is a serious impact on state of mind, discuss with GP.

o The patient's perception is appropriate/realistic.

o This section requires further attention: carry over to the 2nd consultation.

9. What do you think is the cause of your COPD?

o The patient's perception is appropriate/realistic.

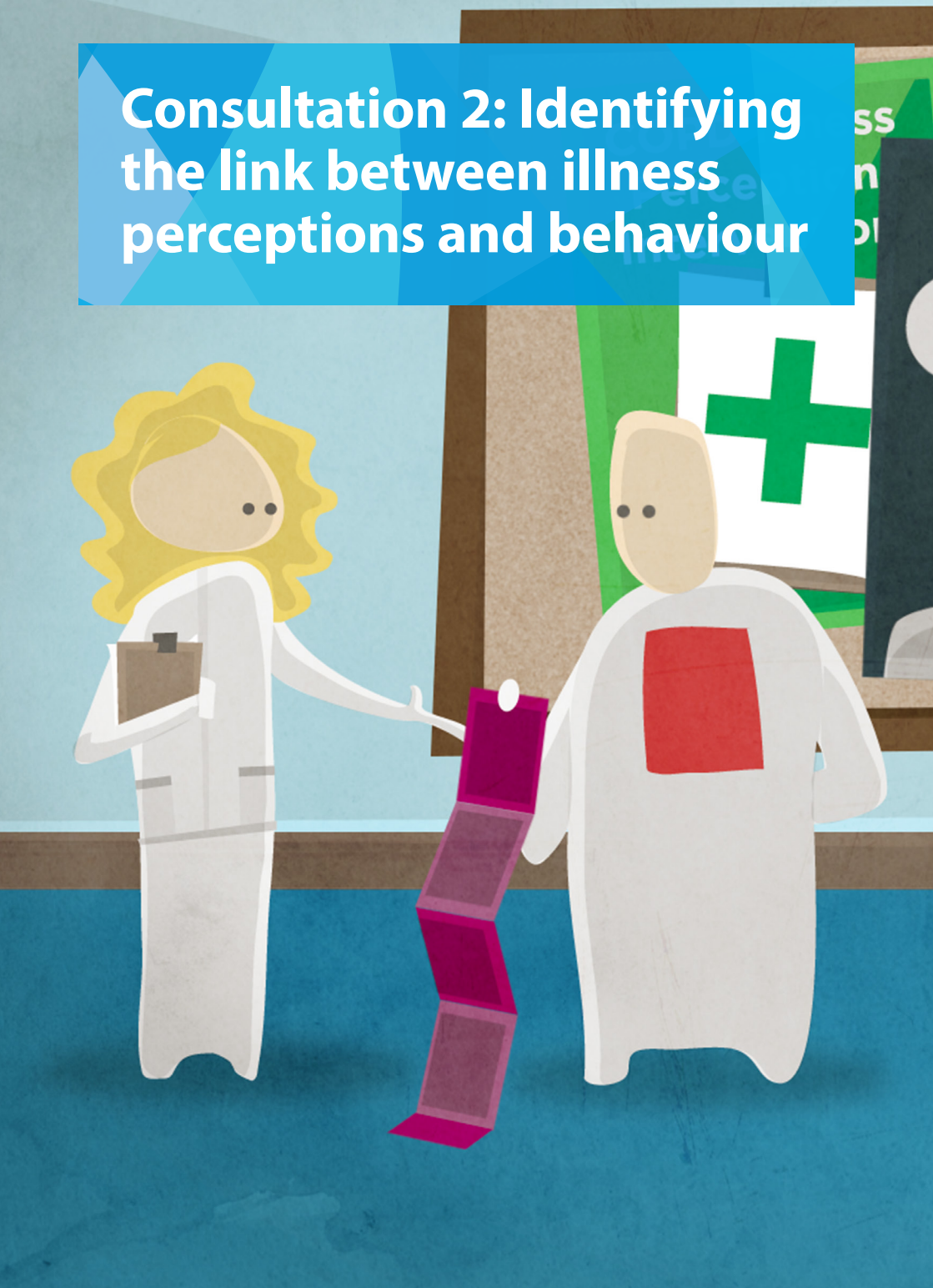
o This section requires further attention: carry over to the 2nd consultation.

Step 4: Conclusion of the first consultation

"I have heard a great deal about you and I feel like I have a good idea of you as a person. Is there anything else you feel is important to discuss with me?"

"We have discussed many topics. Ahead of our next meeting on …., please think about the issues that you find most important."

Consultation 2: Identifying the link between illness perceptions and behaviour



Consultation 2: Identifying the link between illness perceptions and behaviour

In this second consultation, together with the patient, you use the information obtained in the first consultation to identify which perception is most important to the patient and how this can affect behaviour.

You may have gleaned a large volume of information from the first consultation. This can feel chaotic and makes it difficult to decide where to start. You can choose the subject the patient would most like to work with and which he/she finds the most important. You could explain that the volume of information is like a ball of wool and that you are using a thread (a subject or an issue) from this ball with which to start.

Step 1: Explain the purpose and the structure of this consultation

"Last time we discussed many subjects."
"The purpose of this consultation is to discuss those issues that you feel are important to make changes in."

"I would like to refer to your answers again." "Is there an issue that you regard as the most important?"

Step 2: Discuss issues from the B-IPQ, and identify the situation about which something can be done

Provide information about the different topics in the B-IPQ. You can explain that other patients and research have indicated that positive thoughts about the disease and treatment have a positive effect on living with COPD, as well as on daily activities.

"Other patients and research have shown that positive thoughts about COPD and treatment have a positive effect on living with COPD, as well as on daily activities."

"I would like to discuss with you your perceptions of COPD and look at whether anything can be changed. It is important that it is something you want yourself. It is a way of examining in more detail what you would like to achieve and those aspects that you can work on with my help."

1. How much does your COPD affect your life?

o This section requires further attention

"Can you explain how COPD impacts upon your life?"
"Can you tell me what it means to you to live with COPD?"

2. How long do you think your COPD will continue?

o This section requires further attention

Provide an explanation of illnessperception and the duration of COPD.

3. How much control do you feel you have over your COPD?

o This section requires further attention

"I notice from your answer that you feel it is difficult for you to control or influence your COPD."
"Can you tell me what would be required in order to control your COPD?"
"Would it be possible to change something about that so that you are able to better control COPD?"

"Have you ever had the feeling that your COPD was under control?"
"What happened then?"
"Would it be possible to achieve that again?"

4. How much do you think your treatment can help your COPD?

o This section requires further attention

Ask why the patient thinks the treatment does not help.
If the patient's perception is unrealistic, provide an explanation about the treatment, the possibilities and any limitations of the treatment. Identify where there is room for improved treatment. Discuss with the GP if necessary.

"Why do you think treatment does not help?"
"Do you think a different treatment is necessary?"

5. How much do you experience symptoms from your COPD

o This section requires further attention

Together with the patient, identify causes of physical symptoms and find solutions to prevent or reduce them.

Discuss with GP if necessary.

"What physical symptoms do you experience?"
"How do these symptoms affect you?"
"Has anything been done about the symptoms?"
"Do you have any suggestions as to what could be done about these symptoms?"

6. How concerned are you about your COPD?

o This section requires further attention

Discuss the concerns. Allow the patient space to express concerns. If necessary, offer a supporting service (e.g. social services).

"Your answer tells me that you are concerned about COPD, is this correct?"
"Can you tell me more about your concerns?"
"Is there something we can do to ease your concerns about COPD?"

7. How well do you feel you understand your COPD?

o This section requires further attention

Provide the patient with information about COPD and ask whether the patient understands this. Allow the patient to share his/her own experience of COPD and to delve in a little deeper.

Provide more information about COPD if necessary.

8. How much does your COPD affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

If there is a serious impact on state of mind, discuss with GP.

o This section requires further attention

"It is entirely understandable that COPD affects your state of mind."
"COPD is a challenging disease that does not simply go away by itself."
"Can you give an indication of when COPD makes you the most upset, anxious or angry?"

"Anger/anxiety can have a great impact on your state of mind and the things you do."
"Do you know yourself what is necessary to make you feel less angry, anxious or upset?"

9. What do you think is the cause of your COPD?

o This section requires further attention

Provide the patient with information about the causes of COPD and ask whether the patient understands this.

Step 3: discuss with the patient whether there are issues that can be incorporated into a personal treatment plan.

Use the information obtained to discuss with the patient whether there are issues around which a feasible goal or goals with action points can be devised. You can use the personal care plan.

It is important not to lose sight of the fact that you are supporting the patient to achieve and do that in life which he/she considers to have value.

If the patient displays only positive and appropriate perceptions, you can ask whether there are any issues he/she nevertheless considers important and which require attention. If this is not the case, you can leave it here. Do make the third appointment to discuss any loose ends and to round things off.

Personal care plan

1. Long-term goal:

2. Goal for the coming 2 weeks:

3. What do I need to do to achieve this?
- o What?
- o How often?
- o When?

4. Feasibility of the goal

very un-feasible	1	2	3	4	5	6	7	8	9	10	very feasible

5. I will inform the following people of this action plan and ask the following of them:
- o
- o _____

_____

6. Evaluation:
- o Was the goal achieved: Yes/No
- o What do I need in order to achieve the goal?

_____

_____

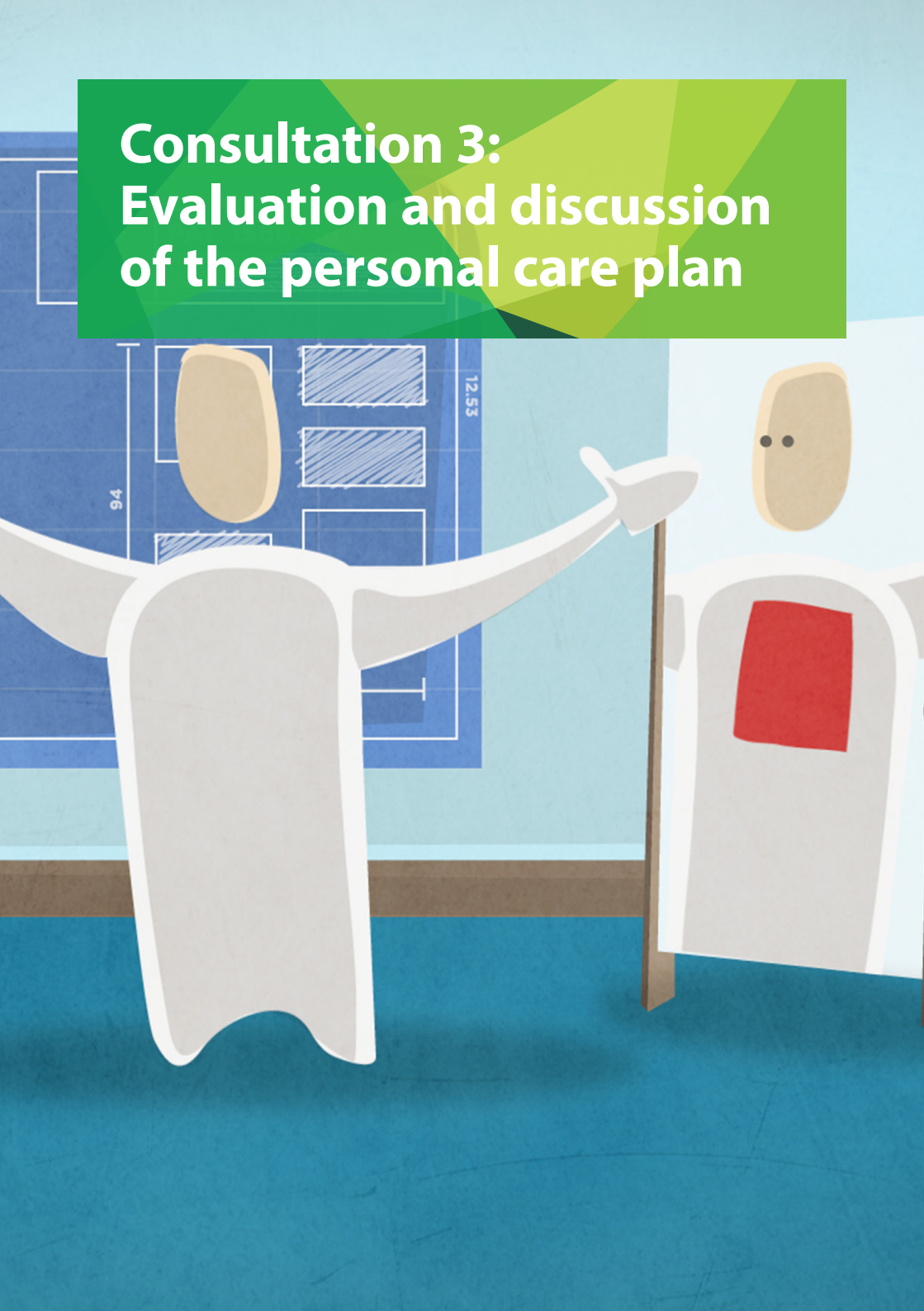
Based on the Cursus Sterk door Werk course (Jansen et al 2011)

Step 4: Conclude the second consultation

"We have now identified action points for you. Do you feel you work with them in the coming weeks?"

"Is there anything else you would like to add before we finish off this consultation?"

Consultation 3: Evaluation and discussion of the personal care plan



Consultation 3: Evaluation and discussion of the personal care plan

In this last consultation, you discuss whether implementation of the personal care plan was successful.

Ask for feedback on what it has been like so far.

Depending on the patient's experience, the goals are adjusted and together you seek to identify new strategies to achieve the goals set.

"How are you now?"
"Were you able to achieve your goal as we discussed?"
"Can you explain why you succeeded/did not succeed?"

"Can you give me a sense of whether you would like to do something about any other issues?"
"Is a new plan required and how can we best agree on one?" "Are you satisfied with our meetings?

If no personal care plan was devised, discuss with the patient how he/she is doing now and what his/her perception is of COPD now.

Discuss what the patient can do going forward together. If necessary, create a new personal care plan.

Appendix 1: Tips for establishing the right tone of conversation

(Based on Weldam et al 2004)

- Pick up on topics of conversation that the patient raises him/herself.
- Use your own intuition to sense people's demeanour.
- Listen to the way somebody says something and observe whether there is tension or emotion, for example.
- Confirm the emotions you observe: "I get the feeling you are angry, is that correct?" or: "I think I detect uncertainty in your voice, is that correct?"
- Use the perceptions of other chronically ill patients to test the patient's own sense of realism, for example: "I have heard from other patients that……"
- Ultimately, the patient decides how he/she wants to do something. That means you have to accept the patient's choices.
- Finally, it may be that you can do no more than accept the behaviour of the patient and keep supporting him/her in managing the consequences as well as possible.

Tips for switching to another theme

"During our last meeting, you said …."
"Last time we spoke about…..……"
"I would like to know whether you work / have hobbies?"
"Do you enjoy your hobbies / job?"
"I would like to cover a few other topics."

(Based on Weldam et al 2004)

Appendix 2: B-IPQ: Brief Illness Perception Questionnaire

B-IPQ

For each question, please circle the score that best represents your view:

1. How much does your COPD affect your life?

no affect at all	0	1	2	3	4	5	6	7	8	9	10	severely affects my life

2. How long do you think your COPD will continue?

a very short time	0	1	2	3	4	5	6	7	8	9	10	forever

3. How much control do you feel you have over your COPD?

absolutely no control	0	1	2	3	4	5	6	7	8	9	10	extreme amount of control

4. How much do you think your treatment can help your COPD?

not at all	0	1	2	3	4	5	6	7	8	9	10	extremely helpful

5. How much do you experience symptoms from your COPD?

no symptoms at all	0	1	2	3	4	5	6	7	8	9	10	many severe symptoms

6. How concerned are you about your COPD?

not at all concerned	0	1	2	3	4	5	6	7	8	9	10	extremely concerned

7. How well do you feel you understand your COPD?

don't understand at all	0	1	2	3	4	5	6	7	8	9	10	I under-stand very clearly

8. How much does your COPD affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

not at all affected emotionally	0	1	2	3	4	5	6	7	8	9	10	extremely affected emotionaly

Please list in rank-order the three most important factors that you believe caused your COPD.

The most important causes for me:

1 _____

2 _____

3 _____

Appendix 3: Personal care plan

Example of personal treatment plan for Conny de Boer (51 years of age)

1. Long-term goal:

To have more energy to do things with my grandchildren.

2. Goal for the coming 2 weeks:

Not to want to do everything at once in the mornings.

3. What do I need to do to achieve this?

- What? Have somebody else do the cleaning.
- How often? Once to twice a week.
- When? On Mondays and Fridays.

4. Feasibility of goal

very unfeasible	1	2	3	4	5	6	7	8	9	10	very feasible
							x				

5. I will inform the following people of this action plan and ask the following of them:

- My husband.
- GP, to request domestic assistance.

6. Evaluation:

- Was the goal achieved: Yes/No
- What do I need in order to achieve the goal?

Based on the Cursus Sterk door Werk course (Jansen DL et al 2011)

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