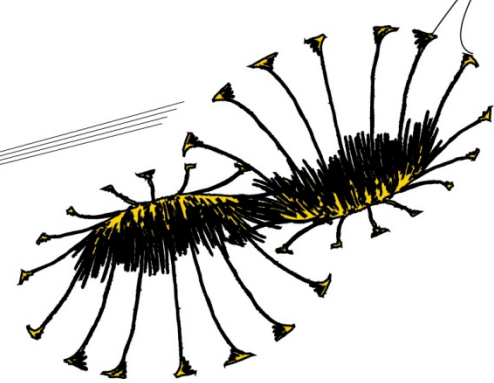



Master thesis:

What are the experiences of COPD patients while
completing the SGRQ-C?



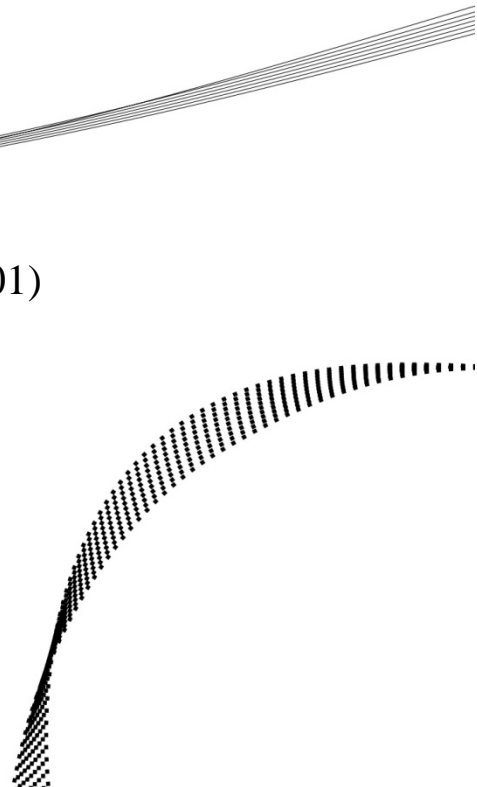
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Abstract

Chronic Obstructive Pulmonary Disease (COPD) is often caused by years of smoking. The consequences range from shortness of breath to total disability. Since the treatment of COPD is aiming for an improvement of health related quality of life (HRQL), it is important to accurately measure both the improvement and deterioration of the HRQL. The Saint George Respiratory Questionnaire (SGRQ) owns the status of the legacy questionnaire in the HRQL research of COPD patients. The objectives of this study were to assess the experiences of COPD patients while completing the Saint George Respiratory Questionnaire for COPD patients (SGRQ-C) and to suggest whether to include items of the SGRQ-C into the item bank of a CAT measuring the quality of life for COPD patients. Twenty COPD patients from the Medisch Spectrum Twente (MST) participated in the study. We applied the Three Step Test Interview (TSTI) to explore misinterpretations and other problems in answering the SGRQ-C items. Respondents had major problems with the interpretation of terms like 'physical exercise', 'sports', 'games' and 'housework' used in items 25, 35 and 38. Respondents asked for a third response option between the two response choices 'true' and 'not true', which were used for 31 items. Moreover, respondents did not read the questions instructions properly and therefore produced a lot of missing data. Overall, respondents were satisfied with the SGRQ-C items. The problems that were found might have been avoided by using the TSTI method during the development of the SGRQ and SGRQ-C. All items except for items 25, 32 and 39 can be included into the item bank of the CAT, after small adjustments.

Preface

The master thesis that is lying in front of you is the result of nine month of research at the Department Health Psychology at the University of Twente.

My first word of thank goes to my two supervisors at the University of Twente for helping me to develop enough research skills to carry out this research. Especially in the beginning when I had health problems and trouble to define a suitable research question.

Second of all I would like to thank the 20 COPD patients that participated in this study.

Last, but not least, I would like to thank my mother, brother, godfather and my friends who supported and motivated me to write this master thesis.

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1. Introduction

1.1 Why do we measure HRQL

Chronic obstructive pulmonary disease (COPD) is a lung disease defined by persistent poor airflow, which results from a breakdown of lung tissue and a dysfunction of the small airways (Mannino & Buist, 2007). COPD is causing a significant disability in work life, family roles, socialization and functions of daily living which are all contributed to a generally decreased health-related quality of life (HRQL). In this context Health services' intention is to support patients to achieve the best possible health in terms of physical and mental functioning, but also with regard to the best possible HRQL (Bendtsen, Leijon, Sommer & Kristenso, 2003). In the last decades medical decision-making research has increasingly focused on HRQL as an important variable (Crosby, Kolotkin & Williams, 2003). HRQL is used as an indicator for measuring the effect of drugs and treatment methods on respiratory diseases from the patient's perspective (Donohue et al., 2002; Monninkhof, van der Valk, van der Palen, van Herwaarden & Zielhuis, 2003; Mahajan, Okamoto, Schaberg, Kellerman & Schoenwetter, 1997). HRQL is a subjective construct, which means that questions can only be answered from the patient's point of view (Stenner, Cooper & Skevington, 2003), which varies from one patient to another. Consequently, HRQL should be measured as individually as possible.

The current study was carried out as part of a research project that aims to develop a multidimensional Computer Adaptive Test (CAT), which will be used to measure the quality of life (QoL) of COPD patients in a more accurate and individual way. A CAT is a system by which the item being administered to the patient is chosen according to his response on the previous item (De Walt, Rothrock, Yount & Stone, 2007). Each domain of QoL will have its own 'item bank' (collection of relevant questions) in the CAT. As part of the CAT development process the researchers are currently working on the development of an COPD specific item bank; this item bank will partly consist of items from legacy questionnaires such as the Saint George Respiratory Questionnaire (SGRQ).

The SGRQ owns the status of the legacy questionnaire in the HRQL research of COPD patients (Paap et al., 2013). It is important to examine the way COPD patients perceive the items of the SGRQ or its COPD specific version the Saint George Respiratory

Questionnaire-C (SGRQ-C), in order to assess if the items are understood by the patients as intended by the developer. This thesis will fill a gap in the literature by focusing on the way SGRQ-C items are perceived by COPD patients; more specifically, for each question the patients' interpretation will be investigated as well as his thought process that underlies the choice of a certain response category.

The prevalence, risk factors and severity of COPD will be reviewed in § 1.2 and § 1.3, followed by a description of COPD treatment in § 1.4 and COPD's impact on patient's quality of life (QoL) in § 1.5. In § 1.6 and § 1.7, literature describing the SGRQ and SGRQ-C will be presented, closing with a short explanation of the method used to measure the patient's experiences while completing the SGRQ-C in § 1.8.

1.2 Prevalence and risk factors

The impact of COPD can be viewed from different perspectives. On the one hand, COPD has a large impact on the patient's life (morbidity, mortality, quality of life) and on the other hand the disease places a substantial burden on society (high health care costs). Understanding the mechanisms underlying the disease, including the risk factors, is highly important both for the individual patient and the society because it can help patients to control their own condition and improve their well-being which naturally reduces the health care costs.

In the Netherlands, 276.000 people were estimated to have a diagnosis of COPD, in January 2007 (Nationaal Kompas Volksgezondheid, 2013). Other sources report 306.000 COPD patients in the year 2000, with a majority of male patients (188.000) (Hoogendoorn, Feenstra & Rutten- van Moelken, 2004). In the year 2011, 6.353 inhabitants died with COPD being the primary cause of death (Nationaal Kompas Volksgezondheid, 2013).

The annual costs for COPD in the year 2000 were about 280 million euros while constantly rising to 415 million euros in 2007 (Nationaal Kompas Volksgezondheid, 2013; Hoogendoorn, Feenstra & Rutten- van Moelken, 2004).

The most important cause for COPD is smoking tobacco (Mannino & Buist, 2007). Approximately 50 % of all smokers may develop COPD, as a Swedish study suggested (Lundbäck et al. 2003). Moreover passive smoking is slightly correlated with the onset of COPD, but the correlation is hard to measure in this case, as it is nearly impossible to gauge the passive exposure to smoke (Coulter, 1998). If patients continue to smoke after COPD is diagnosed, then lung volume will decline more quickly.

1.3 Severity of COPD

The lung damage (level of severity) can be measured, based on the results on a spirometry test called the Forced expiratory volume in one second (FEV¹) which is also used for the diagnosis of COPD. The FEV¹ measures the volume of air that can forcibly be blown out within one second, after strong inhalation. According to the original definition of the Global Initiative for Chronic Obstructive Lung Disease (GOLD) there is an indication for COPD if the volume of air blown out is below 70 % of the predicted value. Furthermore the FEV¹ test is responsible for the patient being categorized into one of the four GOLD stages, which indicate the severity of COPD (Global Initiative for Obstructive Chronic Lung Disease, 2001). The initial GOLD stages as they were first defined in the report of 2001 have been revised in updates of the GOLD report. The respondents in this study were categorized based on the standards used in the GOLD report update of 2007: (1) Mild COPD, the volume of the air blown out will be greater than or equal to 80%; (2) GOLD- II, moderate COPD, FEV¹ volume is between 80 and 50%; (3) GOLD- III, severe COPD, FEV¹ between 50 and 30%; (4) GOLD-IV, very severe COPD, FEV¹ of less than 30 % (Global Initiative for Obstructive Chronic Lung Disease, 2007). Patients being diagnosed with mild COPD get medical treatment from their general practitioner, patients suffering from moderate, severe and very severe COPD get treated by an Pulmonologist (lung expert) (Smeele et al., 2009)

1.4 COPD Treatment

The treatment of COPD requires a drastic change of the patient's life style with a focus on the patient being capable to manage the illness on his own (Self-management) (Gadoury et al., 2005). Important aspects of self-management are to quit smoking, doing respiratory training and increase physical activity (Lakerveld- Heyl et al., 2007). These changes of lifestyle require a lot of coping skills from the patient which have a huge impact on the disease's outcome and perception (Hesselink et al., 2004).

Medical treatment for COPD is only focused on reducing the patient's symptoms (for instance make breathing more comfortable), improving exercise tolerance (being able to exercise) and enhancing the HRQL. It cannot modify the decline in lung function (Celli & MacNee, 2004& Stucki, Stucki, Cieza, Schuurmans, Konstanjsek & Ruof, 2007). Since the

treatment is aiming for an improvement of HRQL, it is important to accurately measure both the improvement and deterioration of the HRQL and the factors related to it.

1.5 The Impact of COPD on the Patient's Quality of Life

For the majority of patients, COPD has a huge impact on their lives which is typically measured by HRQL instruments. Measuring the HRQL enables on the one hand side to distinguish between patients being in a good health condition and those who are in a poor state and on the other hand side to quantify the improvement of the HRQL in response to the therapy (Mahler, 2000). The framework of HRQL is broadly based on the multidimensional perspective of health as physical, psychological and social functioning and well-being. These three domains appear in the health definition of the World Health Organization (WHO), which has been used to enlarge the notion of HRQL beyond the absence of illness to that of complete physical, mental and social well-being (Lipscomb, Gotay & Snyder, 2005).

Patients with different severity levels of COPD suffer from different problems in the three domains of HRQL. Patients in the early stages of COPD only feel disturbance of physical activity during sport or other intensive physical activities. Essential activities of daily life will not be disturbed until FEV¹ scores fall below 50 percent (Jones, 1995).

Patients with severe COPD suffer from its symptoms on a daily basis. Breathlessness and the fear of being breathless have a major impact on the patient's behavior; for instance climbing up hills and taking the stairs become a burden for many COPD patients (Guthrie, Hill & Muers, 2001). Like a patient in a Dutch forum for respiratory diseases patients said: "I now have quite a reasonable stamina and can participate in some sport events (rowing), but walking up the stairs is still quite exhausting." (Daantje, 2013).

In the last years before death, patients suffer from severe breathlessness which restricts their freedom by impairing their mobility and their ability to get out of their home. Additionally the breathlessness comes with panic, anxiety and a loss of weight during the last years of their life. Concerning this matter another patient from the Longforum pointed out: "Your immune system gets weaker and weaker through the weight loss!" (JP, 2013). Most COPD patients feel isolated and deprived of their independence (Elkington, White, Addington- Hall, Higgs & Pettinari, 2004).

HRQL can be measured by using general generic health measures and disease specific measures. Generic instruments quantify a wide range of diseases and disease states, but are relatively insensitive to detect small changes of HRQL (Mahler, 2000). Examples for generic

instruments include the Sickness Impact Profile (SIP), the Short-Form 36 questionnaire (SF-36) and the Nottingham Health Profile (NHP). Disease Specific questionnaires were developed to consider key components that influence the specific diseases, like shortness of breath (dyspnea) in COPD. Example for COPD specific measures are the Chronic Respiratory Questionnaire (CRQ) and the SGRQ (Mahler, 2000). This study will focus on the SGRQ which owns the status of the legacy questionnaire in the research of health related specific quality of life (HRQL) of COPD patients (Paap et. al, 2013).

1.6 The SGRQ

The SGRQ was developed to quantify the impact of diseases of chronicle airflow limitations on health and well-being, to be sufficiently sensitive and to respond to changes in disease activity (Jones, Quirk, Baveystock & Littlejohns, 1992). The questionnaire is a self-administrated health status instrument consisting of 50 items. The questionnaire is divided into 3 subscales: symptoms, activities, and impact. The symptom subscale is concerned with the effect of respiratory symptoms, their frequency and severity. The activity subscale is concerned with activities that cause or are limited by breathlessness and the impact subscale covers a range of aspects concerned with social functioning and psychological disturbance resulting from airway diseases (Jones, 2009).

Each item in the questionnaire has an empirically derived weight, and each of the subscales has its own score. The questionnaire is scored on a scale ranging from 0 to 100, with zero indicating no impairment of patient's quality of life (Jones, 2009).

Karpinski (2005) performed a small meta- analysis of the validation of the US, Swedish, Spanish, Chinese, English and French versions of the SGRQ. Comparing the results of all the six studies together it appears that the SGRQ is sufficiently reliable (Cronbach's alpha), with the symptoms subscale having the lowest reliability of the three subscales. Moreover, a recent study showed that the SGRQ could be shortened from 50 to 31 items without any substantial impact on the reliability (Paap et al., 2013). Since both patients and health professionals prefer shorter to longer instruments, it was recommended to remove the unnecessary items making it easier to fill in the questionnaire.

Some items in the SGRQ are difficult to fill in (feasibility). In the Dutch version of the SGRQ, the reporting periods vary from 'the last four weeks' for the symptoms domain to "usually" or "these days" for the other domains. Consequently the patients have to read the instructions carefully (Rutten-van Mólken, Roos & Van Noord, 1999). Furthermore the

authors of two studies suggested that the fifth and the eighth item ('The frequency of acute attacks of breathing problems' and 'If you have a wheeze, is it worse in the morning?') of the symptoms subscale did not apply to patients with COPD, because these two items are more suitable for asthma difficulties. As a result, the answers to these questions were often missing (Rutten-van Mólken, Roos & Van Noord, 1999; Ferrer et al., 1996). A Swedish study showed that 7 out of 131 patients were not able to complete the whole SGRQ (Stállberg et al., 2009). The results show that some items of the SGRQ might be difficult to complete.

1.7 The SGRQ-C

With the validation of the American translation of the SGRQ came the first permanent modifications of the SGRQ, ten years after its first validation. The reporting period of the symptom items was shortened from 1 year to 1 month (4 weeks), in order to achieve an easier and more reliable recall of the symptoms (Barr et al., 2000).

A second more recent modification of the SGRQ is the St. George Respiratory Questionnaire for COPD patients, also known as the SGRQ-C (Jones, 2012), which is a shortened and improved version of the SGRQ. Eight Items were removed from the original test after applying the Item Response theory (Rasch model), because they showed a poor fit compared to the rest of the items in the same component (symptoms, activity, impact) of the questionnaire. Another one was removed because of its low response rate and the last one delivered disordered responses. Furthermore, the response choices in the symptoms subscale were modified. For example the three options: 'several days a week', 'a few days a month' and 'only with chest infections' used for item three in the SGRQ ('I have shortness of breath') were combined to one response choice in the SGRQ-C ('Several days a week'). The SGRQ-C no longer uses a specific reporting period. The developers of the SGRQ-C were concerned that a reporting period of one year may be too long for reliable and accurate patient recall and thought that a 1-month reporting period, as used in the American translation of the SGRQ, only had "marginally inferior characteristics" to the one year version (Meguro, Barley, Spencer & Jones, 2007). The scoring system of the SGRQ-C was changed by a scoring algorithm to ensure that scores from the new version are equivalent to the original one (Jones, 2012).

The authors concluded that "... the SGRQ-C contains the best of the original items, no longer specifies a recall period, and produces scores equivalent to the original" (Meguro, Barley, Spencer & Jones, 2007). Still the SGRQ-C does not seem to be widely used in COPD

research, as the GOLD standards published in 2011 still recommend the SGRQ to measure the health related quality of life of COPD patients (Yawn, 2012). It is not well researched until now and some of the weak sides of the SGRQ described above remain, despite of the improvements of the SGRQ-C. The SGRQ-C reduced the number of items from 50 to 40, but a recent study suggests that the number of items could be decreased even further (Paap et al., 2013). Overall, it is interesting to see what COPD patients experience while completing the SGRQ-C. The full version of the Dutch version of the SGRQ-C can be found in *Appendix A*.

1.8 Study method/research question

This study will examine the way COPD patients perceive the SGRQ-C and its items, by using the Three Step Test interview (TSTI). The TSTI contains two parts, the think- aloud method and the cognitive interview. These two parts are further divided into three steps, which enable the understanding of the thought process or decision making of someone performing a specific task (Hak, van der Veer & Jansen, 2008).

Tourangeau (1984) describes the response process as consisting of four main cognitive steps: Comprehension, Retrieval, Judgment and Communication. A problem can occur in any of the four steps, when a subject responds to an item in a questionnaire. This can but does not have to lead to 'data error', for example a score being too high on the SGRQ-C that does not reflect the true HRQL of the patient. The TSTI identifies the cause of this data error by producing observational data on actual response behavior of respondents who respond to the items of the questionnaire (interaction between the respondent and the questionnaire). A big part of this response behavior consists of 'thinking' and is therefore hidden from the observer ('Black Box'); the think aloud technique makes it observable, as respondents have to say aloud what they are thinking while they are thinking it. Additionally the Respondents are asked about their own interpretation of their behavior ('debriefing cognitive interview') (Jansen & Halk, 2005 & Hak, van der Veer & Jansen, 2008). The use of this method makes it possible to find problems with the completion of the items that were not observable without using the TSTI method.

The TSTI method has already been used for testing several existing questionnaires. In a recent example, Hak, van der Veer & Jansen (2008) used the TSTI method to examine the underlying processes that occur when patients fill out a self-completion questionnaire on alcohol consumption. Most of the problems that were observed originated from mismatches between the 'theory' underlying the question and the respondent's real life (lifestyle,

biographies or other peculiarities of the respondents) (Hak, van der Veer & Jansen, 2008). For example a question about the drinking habits of the respondent in the last 2 weeks is supposed to measure how much alcohol the respondent drinks on regular basis ('theory'). As the respondent has been on vacation the last 2 weeks, he has been drinking a lot more during this vacation than he would do during a regular working week ('real life'). No research is available about the patient's perception of the SGRQ-C's items; therefore the main focus of this study is the patient's perspective on the SGRQ-C. The TSTI will be used to answer the following research question:

- What are the experiences of COPD patients completing the SGRQ-C?

2. Method

2.1 Three- Step Test Interview (TSTI)

The process of answering questions in a self- report questionnaire, like the SGRQ-C, can be seen as an interaction between the COPD patient and the questionnaire. As mentioned in the introduction, this interaction process is not visible for the researcher. They can only see what is produced (completed items), but they cannot observe the completion process (response process). The TSTI is used to make the process observable (Hak, van der Veer & Jansen, 2008).

The method consists of two parts, a think aloud method and a cognitive interview. These two parts are further divided into three steps, to test the process underlying the completion of a questionnaire. The first step is the think aloud method. Respondents are invited to verbalize their thoughts while completing the questionnaire. During the first step the observer does not comment but only observes, listens and takes real time notes (Jansen & Hak, 2005). The performance of the think aloud method can be difficult for some patients as it is not very common to verbalize your thoughts. Furthermore 'bias in subject information processing' is a common problem. 'Bias in subject information processing', means that respondents invest clearly more amount of mental effort to answer the questions in the think aloud procedure than they would normally do while filling in a questionnaire (Willis, 1999). This extra mental effort might influence the respondent to give another answer than he would in a normal self-completion situation.

The second step of the TSTI, a retrospective interview fills gaps in the observational data. The observer asks questions about things that he has observed, but where he feels that the data is incomplete (Hak, van der Veer & Jansen, 2008). Respondents should only report about things they felt or thought during the first step, not what they feel or think about the actions afterwards (retrospective) (Hak, van der Veer & Ommundsen, 2006)

During the third step respondents are interviewed and encouraged to add more data and explain their response behavior. Additionally, respondents can suggest ways to improve the questionnaire (Hak, van der Veer & Jansen, 2008; Jansen & Hak, 2005). Cognitive debriefing interviews like in the third step allow direct input from respondents on the item content, format and understandability of a questionnaire (Irwin, Varni, Yeatts & De Walt, 2009).

According to Ericsson & Simon (1993), the second step of the interview, the retrospective think aloud, has to be executed within five minutes after filling in the actual item. If the time period between step one and step two takes more than five minutes then the respondent will have problems to remember their thoughts in the first step. Therefore, we choose to repeat the three steps of the TSTI consecutively for blocks of items. The blocks of items were based on similarities in content of the items and quantity of items. The seven blocks of items contained items 1 to 7, 8 to 13, 14 to 19, 20 to 26, 27 to 34, 35 to 39 and 40.

2.2 Procedure

Before the beginning of the first interview, a number of 10 to 20 respondents was proposed to be sufficient to get enough information about the experiences of COPD patients completing the SGRQ-C. A total of 20 COPD patients were recruited from the department 'pulmonary medicine' of the Medisch Spectrum Twente (MST) (Purposive sampling) (Marshall, 1996). The inclusion criteria for participating in this study were a medical diagnosis of COPD, sufficient oral and written mastery of the Dutch language and being able to answer questions in a face-to-face interview and completing a questionnaire.

Nine of the 20 respondents were inpatients who already been staying in the hospital for some days and were in a stable condition. During the doctor's visit the interviewer accompanied the responsible medical assistants to ask the patients if they were willing to participate in the study. Eight of these nine interviews were administered in the patient's room, which was normally shared with about 2 other patients and frequently visited by

hospital staff. Only one patient was able to walk to a separate room (daycare room), which provided more silence and anonymity for the respondent.

The other 11 patients were recruited from the polyclinic department 'pulmonary medicine'. The patients were called to schedule an interview meeting in a private room in the MST department 'pulmonary medicine' or at the patient's home. An invitation letter was sent to the respondents containing the time and date of the appointment. Five interviews were conducted at the patients' home while the other six were performed at the clinic. Every patient had to fill in the informed consent sheet prior to the start of the interview. See *Appendix B* for the information letter. See *Appendix C* for the informed consent sheet.

The interviews lasted about 20 to 65 minutes. The interviews were recorded by using an audio recorder. Before the beginning of the interviews it was emphasized for the respondents that the goal of the study was to test the questionnaire and not to test the respondents. Furthermore, it was stated that the data was anonymized and no information in the report would identify those who participated.

Nineteen of the 20 TSTI interviews were conducted by the same interviewer. He was trained by role-playing in which possible reactions of patients to the TSTI procedure were simulated and advantages and disadvantages of interviewer reactions were discussed. One interview was held by another researcher who was also trained in the procedure of the TSTI.

The ethic Committee of the University of Twente approved the study proposal on the 31th of October. The study proposal clarified that the study was following the ethical standards for research in the Netherlands. There were no significant risks related to the interview. Considering the nature of the interview (highly structured), no emotional strain was expected.

2.3 Respondents

Twenty COPD patients participated in the study; all 20 respondents were patients at the MST department 'pulmonary medicine'. Thirteen of the respondents were female and seven were male. The mean age was 63.25 years ($SD=11.37$). The youngest respondent was 45 and the oldest was 84 years old. See table 1 for an overview of the descriptive statistics.

Table 1

Gender, Age and Severity Stage of Respondents

Respondent	Gender	Age	Severity COPD	Inpatient/ Outpatient
R1	Male	54	GOLD 4	Out
R2	Male	51	GOLD 2	Out
R3	Male	54	GOLD 4	Out
R4	Female	83	GOLD 2	In
R5	Female	67	GOLD 2	In
R6	Female	68	GOLD 3	Out
R7	Female	75	GOLD 3	In
R8	Female	84	GOLD 2	Out
R9	Female	67	GOLD 3	Out
R10	Female	60	GOLD 4	In
R11	Female	64	GOLD 4	In
R12	Male	56	GOLD 2	Out
R13	Female	54	GOLD 4	Out
R14	Female	45	GOLD 4	Out
R15	Male	82	GOLD 4	In
R16	Male	58	GOLD 4	In
R17	Female	60	GOLD 2	In
R18	Male	58	GOLD 4	In
R19	Female	59	GOLD 4	Out
R20	Female	66	GOLD 2	Out

2.4 Introduction and execution of the TSTI procedure

As per protocol, the interviewer informed the respondent that the aim of the interview is to test the questionnaire not the respondent. In this context it was also important to brief the patient that each item would be approached in three steps. First the completion of the items and afterwards an evaluation of what happened. The patients should know that the third step of the interview was the right time to express their opinions, ideas and proposals (Hak, van der Veer & Jansen, 2004). The three steps of the TSTI procedure were introduced to the respondent in the following way:

Step 1: The aim of this first step was to observe what comes to the patient's mind while answering the questions in the SGRQ-C. The think aloud procedure was unusual for most respondents and had to be practiced first. After this first training of the think aloud technique it was important that the respondent got appropriate feedback from the interviewer. This feedback reinforced good performance and gave more explanation about what was expected from the patients:

“Please say aloud what you think as you think it while filling in the item. You do not have to explain or justify your thoughts or answers, but only say aloud what naturally goes through your mind while answering the questions. Since this may be the first time that you perform this task, we will undertake an exercise first”.

Step 2: The aim of the second step was to fill the gaps of data gathered in step 1, to get a more complete reconstruction of the thought process the patient had while filling in the item and identify problems.

“The questions that I would like you to answer in the second step depend on my observations from step 1. For example: You read the question out loud and then you hesitated to verbalize your thoughts. What were you thinking at the moment?”

Step 3: In this part respondents could explain their response behavior, comment on their definition of terms or give general opinions about the questionnaire or their items. This took place in the form of a semi structured interview, the specific probes depended on the observations from step 1 and 2. One example for a question is: “Would you like to add something?” See *Appendix D* for more information regarding the introduction and execution of the TSTI procedure.

2.5 Analysis of the data

All interviews were fully transcribed verbatim. Afterwards the transcripts and the observations taken during the interview were scanned for problematic experiences of COPD patients. The researcher was looking for problematic experiences such as: (1) The respondent stated that the item is difficult; (2) The respondent had suggestions for improvement of an item; (3) The respondent asked the interviewer about the meaning of certain words or terms in the item; (4) The respondent had certain criticism about an item; (5) The respondent had problems with the response options. These problematic experiences of all respondents were assembled in a list per item and then categorized into two categories. It was investigated if the problems were comments on and problems with the question or with the response choices.

The self-completion data produced in the first step of the interview was used to calculate the mean scores, subscores and inter-item correlation. To determine the reliability Guttman's lambda 2 was calculated.

3. Results

3.1 SGRQ-C scores

The average score on the SGRQ-C was 56.45 ($SD = 22.72$). The scores were widely spread with respondent 20 scoring 20.6 and respondent 15 having a total score of 91.8. The averages on the three subscales of the SGRQ-C were: (1) Symptoms 65.3 ($SD = 22.8$); (2) Activity 68.1 ($SD = 28.7$); (3) Impact 43.8 ($SD = 24.0$). Respondent 16's activity score was omitted when calculating the average activity subscore, due to three missing values in the activity scale (Jones, 2012).

The 'Minimal Clinical Important Difference' (MCID) was used to identify differences between groups because of the small amount of participants ($N=20$) (Gatschel, Lurie & Mayer, 2010). The SGRQ-C manual defines the "threshold for a clinical significant difference between groups of patients and for changes within patients groups as four units" (Jones, 2012). The total score of women was more than four points higher than that of the men. Respondents with COPD GOLD IV also scored more than four points higher than respondents with COPD GOLD II + III. No MICD was found between inpatients and outpatients.

Striking scores on the subscales were observed for respondent 5 who scored zero on the Activity subscale, respondent 20 who scored zero on the Impact scale and respondent 15 who scored the full 100 points on the Symptoms scale. See Table 2 for an overview of all scores on the SGRQ-C and its subscales.

Table 2

Respondents' Scores on the SGRQ-C and its Subscales.

Respondent	SGRQ- C Score	Symptoms score	Activity score	Impact score
R1	66.80	91.20	99.80	38.81
R2	31.54	75.86	7.58	30.60
R3	41.72	54.42	56.16	26.63
R4	59.43	46.66	81.17	52.95
R5	20.94	29.18	0.00	30.58
R6	44.49	57.80	75.13	21.72
R7	71.64	78.10	91.84	57.41
R8	64.70	37.67	81.87	65.25
R9	87.70	97.05	91.84	82.03
R10	34.56	55.65	65.87	10.10
R11	74.31	54.91	84.56	74.91
R12	36.60	52.28	37.14	30.91
R13	69.79	97.32	91.76	46.39
R14	89.35	61.12	83.42	54.09
R15	91.86	100.00	91.85	79.46
R16	36.03	55.05	-	12.30
R17	43.21	65.31	45.87	33.01
R18	64.19	83.49	60.44	59.81
R19	79.66	89.10	91.08	69.51
R20	20.63	23.74	56.14	0.00
Mean	56.45	65.30	68.10	43.80

3.2 Distribution of problems across respondents

Every respondent reported problems with at least one of the items of the SGRQ-C. The number of problems included all comments and all items that were not completed (missing values). The average amount of problems per respondent was 7.9.

The ten COPD GOLD IV respondents reported more problems (9.4 problems on average), than the other ten respondents (< GOLD IV) (6.1 problems on average). Inpatients reported fewer problems while completing the questionnaire (average of 6.4 comments) than outpatients (average of 8.8 comments). Additionally, men (average of 9.4 comments) reported more problems than women (average of 6.7 comments).

Striking were the amount of comments or problems of respondent 3 who failed to fill in 14 items and respondent 4 who had no comments, but just failed to fill in three items. Respondent 3 misinterpreted the instructions of questions 9 and 10. He assumed that he only had to fill in an item if they had problem with this activity. Eight of his 14 missing values

resulted from this misinterpretation. Table 3 illustrates the exact number of problems, comments and missing values for each respondent.

Table 3

Number of Problems, Comments and Missing Values per Respondent.

Respondent	Problems	Comments	Missing values
R10	2	2	0
R9	3	2	1
R6	3	3	0
R4	3	0	3
R12	5	5	0
R15	5	2	3
R16	5	1	4
R11	5	3	2
R2	5	5	0
R5	5	5	0
R7	7	7	0
R8	7	4	3
R13	8	8	0
R19	8	6	2
R14	12	11	1
R17	12	11	1
R20	12	8	4
R18	15	15	0
R1	16	16	0
R3	20	6	14
Mean	7.90	5.00	1.90

3.3 Problems per Item, Inter-Item correlation, Missing Values and Reliability

Table 4 illustrates that the respondents had problems with items of all subscales of the SGRQ- C. The average number of problems per item was similar for the three subscales of the SGRQ-C: (1) Symptoms 3.9 problems per item; (2) Activity 3.7 problems per item; (3) Impact 4.2 problems per item.

Item 7 was the only item in the questionnaire that did not cause any problems. Items 25, 35 and 40 of the Impact subscale were the three items which created the most problems of all SGRQ-C items.

The number of negative correlations with other items had a small negative correlation with the amount of problems per item $r = -0.15$. Every item except item 11 and 39 had at least two negative correlations with other items of the questionnaire. Item 14 and 39 were

removed from the inter-item correlation table as the determinant of the covariance was zero or nearly zero. None of the respondents filled 'true' in for item 39 (*'Ik kan niet ver van mijn bed of stoel komen'*) and only respondents 11, 15 and 19, which are all respondents with high total scores, filled 'true' in for item 14.

There was a high amount of missing data as 21 items were not completed by every respondent and only nine respondents filled in every item. The small amount of respondents who filled in every item of the questionnaire made it nearly impossible to calculate the reliability (Guttman's Lambda 2) of the questionnaire and its subscales. Lambda 2 was only calculated for the Symptoms subscales ($\lambda_2 = 0.72$) of the questionnaire as it was the only subscale that was fully completed by all respondents.

Table 4

Number of Problems, Comments, Missing Values and Negative Correlations with other Items, per Item.

Item	Subscale	Problems	Comments	Missing values	Negative inter-item correlation
7	Symptoms	0	0	0	2
2	Symptoms	2	2	0	6
4	Symptoms	2	2	0	13
1	Symptoms	4	4	0	6
3	Symptoms	4	4	0	7
6	Symptoms	7	7	0	7
5	Symptoms	8	8	0	3
12	Activity	1	0	1	6
27	Activity	1	1	0	4
31	Activity	1	0	1	6
9	Activity	2	0	2	3
29	Activity	2	2	0	6
28	Activity	3	3	0	4
13	Activity	4	2	2	5
32	Activity	4	4	0	6
10	Activity	5	1	4	11
30	Activity	5	3	2	5
11	Activity	6	2	4	0
33	Activity	6	6	0	6
34	Activity	8	7	1	6
15	Impact	1	0	1	6
19	Impact	1	1	0	6
23	Impact	1	1	0	22
14	Impact	2	1	1	-
18	Impact	2	1	1	10
16	Impact	3	2	1	5
17	Impact	3	1	2	9
20	Impact	3	3	0	16
22	Impact	3	3	0	21
26	Impact	3	2	1	10
36	Impact	3	2	1	5
37	Impact	3	3	0	10
24	Impact	4	4	0	19
38	Impact	4	3	1	0
8	Impact	5	5	0	4
21	Impact	5	4	1	18
39	Impact	5	4	1	-
25	Impact	9	7	2	2
40	Impact	11	4	7	2
35	Impact	12	10	2	11
Mean	-	3.95	2.97	0.98	-

3.4 Results of the SGRQ-C based on the TSTI

In the following section, results of the SGRQ-C based on the TSTI method are presented. For a better overview, the results are presented for each subscale separately (Symptoms, Activity and Impact). The results of each item are further divided into comments on and problems with the question and response choices.

3.4.1 Results of the Symptoms scale of the SGRQ- C

Instructions items 1 to 7:

Vragen over hoeveel ademhalingsproblemen u heeft.

Wilt u a.u.b. één hokje aankruisen voor elke vraag.

Item 1: Ik hoest:

de meeste dagen v.d. week..... a

meerdere dagen v.d. week b

alleen bij een luchtweginfectie..... c

helemaal niet d

Four respondents (R1, R14, R18 & R20) had problems with or comments on item 1. All of the four comments were directed at the response options. Respondent 1 missed the option ‘seven days per week’ (*‘Zeven dagen per week.’*). Respondent 14 wanted the option ‘sometimes’, which is the English translation of the Dutch word ‘soms’. Respondent 18 said that that there is no right response choice for him, but he did not say which response option he was missing. Respondent 20 suggested to add the fifth response option ‘once in a while’ (*‘Afen toe.’*) between the options ‘only with a chest infection’ and ‘not at all’ (*‘Afen toe hoest ik maar, maar die staat er niet bij.’*)

Item 2: Ik geef slijm op:

de meeste dagen v.d. week..... a

meerdere dagen v.d. week b

alleen bij een luchtweginfectie... c

helemaal niet d

Two respondents (R1 & R3) had comments on item 2. Both respondents were not content with the response choices. They were both missing a response choice. Respondent 1 said he missed the response choice 'seven days a week' ('*Zeven dagen per week.*') while respondent 2 missed the answer 'mostly in the morning' ('*Dat is meestal 's morgens, (..) maar die staat er niet bij.*').

Item 3: *Ik ben kortademig.*

de meeste dagen v.d. week..... a

meerdere dagen v.d. week b

helemaal niet c

The comments (R1, R8, R14 & R20) on item 3 also emphasized problems with the response format. Two respondents (R1, R14) missed the response choice 'seven days per week'. Respondent 1 called it 'seven days a week' ('*zeven dagen per week.*') while respondent 14 called it 'every day' ('*Ik ben elke dag, maar die staat er niet tussen.*') Respondent 8 was missing the response choice 'only with a chest infection' which was provided in items 1, 2 and 4 ('*Misschien wat zei je met luchtweginfectie.*'). Furthermore respondent 20 suggested to add the fourth response option 'once in a while' ('*Af en toe.*') between the options 'several days a week' and 'not at all' ('*Ja, daar mis ik de (.) tussenstation. Je hebt de meeste dagen of helemaal niet.*')

Item 4: *Ik heb last van piepende ademhaling.*

de meeste dagen v.d. week..... a

meerdere dagen v.d. week b

een paar dagen v.d. maand..... c

alleen bij een luchtweginfectie..... d

helemaal niet e

Two respondents (R1 & R18) had trouble to fill in item 4. Respondent 1 said that the weather had great influence on his wheezing (*'Als het er niet vochtig is en geen mist. Heb ik er geen last van.'*). He concluded to fill in 'only with chest infection', because he often had chest infections when the weather was humid and cold. His suggestion was to add the item 'does the weather have influence on your wheezing' (*'Heeft het weer, heeft het invloed op u piepende ademhaling?'*). Respondent 18 missed the response choice 'every day' (*'Maar bij mij is het echt wel elke dag.'*).

Item 5: Hoeveel zware of zeer onaangename aanvallen van ademhalingsproblemen had u gedurende het afgelopen jaar?

3 of meer aanvallen a

1 of 2 aanvallen b

Nooit c

Eight respondents (R2, R8, R9, R11, R13, R14, R18 & R19) had comments on item 5. Respondent 9 said that he did not understand the question (*'Dat begrijp ik ook niet.'*) and respondent 11 called it a horrible question (*'Oh dat is een rot vraag.'*). Respondents 2, 8 and 9 were not pleased with the time span used in the question. They said that 'one year' is a too long period of time to recall how many attacks they had (*'En dat per jaar vind ik wel heel ruim om om te zien.'*). All three of them suggested reducing the period of time to 'one month' (*'Afgelopen maand bijvoorbeeld.'*).

Respondent 18 was not content about the response choices (*'Ja, nooit is nooit, bestaat nooit.'*). Respondents 13 and 14 explained that three attacks of chest trouble per year did not represent their amount of attacks because they had an amount of attacks, which is significantly higher. They suggested asking an open question (*'Dat moet je dan eigenlijk als open vraag laten zo iets.'*).

Item 6: Hoe vaak heeft u goede dagen met weinig last van ademhalingsproblemen.

- geen a
- een paar goede dagen b
- de meeste dagen zijn goed c
- elke dag is goed..... d

Seven respondents (R1, R3, R5, R6, R7, R14 & R19) had comments or problems with item 6. Respondent 7 was missing a period of time in the question. He suggested asking, ‘How many good days do people have per week or per month’ (*‘Ja, hoe vaak in de week of in de maand.’*). Respondent 3 suggested adding the word ‘physical exertion’ (*‘inspanning’*) to the question, but he did not specify how to do it exactly. Respondents 1 and 14 both stated that the weather had a big influence on the number of good days they had. Respondent 14 specified that rainy days have a negative influence on this number (*‘Als je zeg maar heel veel regen hebt dan blijf ik liefst in bed’*). Respondent 1 only stated that the weather in general is of influence. Respondent 5, 6 and 19 had a problem with the interpretation of the expression ‘good days’ (*‘goede dagen’*). They all thought that ‘good days’ is too strong, because they have no days without breathing problems. Respondent 19 suggested replacing the term ‘good days’ with the term ‘better days’ (*‘Of het vervangen kan worden door betere dagen.’*).

Item 7: Als U last heeft van piepen op de borst is het dan ’s ochtends het ergste?

- Nee.....
- Ja.....

There were no comments on or problems with item 7.

General Comment on the symptoms section & instructions:

Vragen over hoeveel ademhalingsproblemen u heeft.

Wilt u a.u.b. één hokje aankruisen voor elke vraag

Five respondents (R2, R7, R11, R17 & R18) had general comments on the items of the Symptoms section. Respondent 18 and 11 were missing items. Respondent 18 wanted an item about problems with riding a bike (*'Fietsen kan ik nu ook niet.'*) and respondent 11 missed questions about physical exertion (*'Bij inspanning, zo dat.'*). Respondent 7, 11 and 17 were all saying that the weather had influence on their well-being; that is why they wanted weather to be integrated into the questionnaire. Respondent 1 mentioned that he had less trouble with his disease when it was cold outside (*'Ja, ik zit precies andersom dan bij de anderen. Ik ben heel weer weersgevoelig, maar in de winter gaat het bij mij heel goed.'*). Respondent 2 suggested that the questionnaire should state a clear period of time to answer questions 1 through 7. He suggested adding the period of time, 'at this moment' or 'last month' (*'Ja, op dit moment of op de laatste maand.'*).

Short summary of the symptoms subscale:

The Symptoms subscale was the only subscale without missing values. The respondents only had major problems with item 5 and 6. Respondents thought that the time period of 'one year', used in item 5, is too long to recall how many attacks they had. Furthermore, they were not content with the response choices of item 5. Item 6 was problematic because respondents struggled with the interpretation of the term 'good days'. The other five items caused only minor problems. Respondents missed response choices that could be added easily. Moreover, respondents stated that weather seems to be of influence on the frequency of their respiratory symptoms.

3.4.2 Results of the Activity Scale of the SGRQ- C

Instructions items 9 to 13:

Vragen over welke activiteiten u normaal gesproken kortademig maken.

Kruist u alstublieft bij elke bewering het hokje aan dat momenteel? of, de afgelopen dagen? het meest op u van toepassing is.

<i>Item 9:</i>	<i>Wassen of aankleden.</i>	Waar	Niet waar
		<input type="checkbox"/>	<input type="checkbox"/>

There were no comments on item 9. Respondents 3 and 20 did not fill in the item. Both respondents also did not fill in item 10 and 11. They assumed that they only had to fill in an item if they had a problem with this activity.

Item 10: **Thuis rondlopen.**

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

One respondent (R1) had trouble filling in item 10 and four respondents (R3, R4, R16 & R20) did not fill in the item. Respondent 1 only had a minor comment on item 10. He said that the weather had influence on his ability to walk around the home (*'Rondlopen thuis heeft weer te maken met het weer.'*).

Respondents 3 and 4 did not fill in item 10 because they misunderstood the instructions; they thought they should only fill in items if they had problems with this activity. Respondent 16 did not fill in item 10, because he did not know if he was able to walk around the home, after not having left the bed in the hospital for more than a week (*'Weet ik ook nog niet.'*).

Item 11: **Buiten lopen op vlak terrein.**

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Two respondents (R15 & R17) had comments on item 11, three respondents (R3, R16, R20) did not fill in the item and one respondent (R14) did not fill in the item correctly. Respondent 15 said that the item was difficult to understand, but could not explain why (*'G: Ik vindt de vraag moeilijk gesteld.'*). Respondent 17 was missing a specified distance as an indicator of how long to walk outside (*'Kun je tien meter lopen of kun je twintig meter lopen, daar gaat het om.'*).

Respondents 3 and 20 did not fill in item 11 due to the same reason they did not fill in items 9 and 10. Respondent 16 did not fill in item 11 because he was still in the hospital and was not sure if he was able to walk around outside on the level (*'Buiten lopen weet ik ook nog niet'*). Respondent 14 gave two opposite answers; he filled in 'true' and 'not true', because if he was able to walk outside or not was dependent on the weather (*'Hoe het met de weer is. Als het dit weer is, ik ben net gelopen van de parkeergarage naar rolstoel.'*).

Item 12: *De trap opgaan (één verdieping).* Waar Niet waar

There were no comments on item 12. Only respondent 4 did not fill in this item, because she misunderstood the instructions; she assumed she should only fill in items if he had a problem with the activity.

Item 13: *Een helling oplopen.* Waar Niet waar

Two respondents (R2 & R17) had comments on item 13 and two respondents (R16 & R19) did not fill in the item. Respondents 2 and 17 where not content with the word ‘hill’ (*‘Helling’*). They both wanted a more exact explanation of a hill. Respondent 17 made the suggestion to differentiate between a small, a medium and a steep hill (*‘Ik zou er bijzetten van een steile helling, middel of een kleine helling.’*).

Respondent 4 and 19 did not fill in the item, because they were incapable of walking up a hill (*‘Eh, een helling oplopen, nou dat doe ik nooit. Het is niet van toepassing.’*). Respondent 16 did not fill in the items because he was admitted to the hospital and was not sure if he was able to walk up a hill.

General Comment on items 9 to 13 & instructions:

Vragen over welke activiteiten u normaal gesproken kortademig maken.

Kruist u alstublieft bij elke bewering het hokje aan dat momenteel? of, de afgelopen dagen? het meest op u van toepassing is.

Nine respondents (R1, R5, R6, R7, R10, R13, R14, R19 & R20) had general comments or problems filling in items 9 to 13. Respondent 1 was missing items that are concerned with ‘physical exertion’ and wanted to change the time period used in the instruction of the question from ‘currently or recent days’(‘Momenteel of afgelopen dagen.’) to ‘last month’(afgelopen maand’). Respondent 5 missed items about ‘riding a bike’ (‘fietsen’) and ‘hiking’ (‘wandelen’). Furthermore he wanted to change the instruction

sentence; ‘questions about what activities usually make you feel breathless’ (*‘Vragen over welke activiteiten u normaal gesproken kortademig maken.’*), to questions about which activities usually make you become breathless (*‘Vragen van welke activiteiten u normaal gesproken kortademig wordt.’*). Respondent six stated that the thinking aloud technique forced him to overthink his decisions and making more accurate decisions (*‘Dat moet ik hardop praten en dan moet ik wat nadenken. En dan kom je tot de conclusie dat het waar is of niet waar is.’*). Respondents 7 and 13 were missing an item about ‘housework’ or ‘domestic work’ (*‘huishoudelijk werk.’*). Respondent 19 was not sure how to fill in some of the items from question 9, because she received home care (*‘Thuiszorg’*). People came to her home helping her get dressed in the morning and to get ready for bed in the evening (*‘Dus het is echt eh ik neem aan dat jullie daarvan uitgaan dat ik het zelf doe en dat is dus in mijn geval niet zo.’*). Respondent 10 and 20 only filled in the items with the activities that they had problems with in the first step until the interviewer explained to them that they could also fill in items with ‘not true’. Respondent 20 commented this request with the information that the questionnaire could remove the second response option ‘not true’ which would have no effect on the questionnaire (*‘Zij kunnen het tweede hoekje ook eigenlijk weglaten, toch?’*). Respondent 14 demanded sometimes (*‘soms’*) as a third response choice.

Instructions items 27 to 34:

Dit zijn vragen over hoe uw activiteiten beïnvloed kunnen worden door uw ademhalingsproblemen.

Kruist u alstublieft bij elke bewering het hokje aan dat op u van toepassing is door uw ademhalingsproblemen:

Item 27: Ik doe er lang over om mij te wassen of aan te kleden.

Waar

Niet waar

One respondent (R1) had a comment on item 27. The respondent stated that he missed a third response choice ‘sometimes’ (*‘soms’*), because it depends on his daily condition if it took him long time to get washed or dressed (*‘Daar heb ik waar neergezet maar wil ik daar ook soms daarbij willen hebben. Want de ene keer gaat het beter dan de andere dag.’*).

Item 28: *Ik kan niet in bad gaan of een douche nemen, of het kost veel tijd.*

Waar Niet waar

Three respondents (R6, R17 & R18) had comments on item 28. All three respondents had problems with the question. Respondent 17 wanted the location ‘wet humid areas’ (*‘Natte vochtige ruimtes.’*) to be included in the question. Respondent 6 and 18 did not like the term ‘it takes a lot of time’ (*‘Het kost veel tijd.’*). Respondent 6 said that ‘it takes a lot of time’ (*‘het kost veel tijd’*) is not clearly defined and that ‘it takes more time than in the past’ (*‘Het kost meer tijd dan vroeger’*) would be a better to be used in the question (*‘ Kost veel tijd, wat is veel tijd? Maar het kost meer tijd dan vroeger, dus is waar.’*).

Item 29: *Ik loop langzamer dan andere mensen, of ik stop om uit te rusten.*

Waar Niet waar

Two respondents (R7 & R18) had a comment on item 29 and one respondent did not fill in the item (R20). The comments of respondents 7 and 18 are both linked to item 32. The respondents stated that both items are similar and that one of them should be removed, respondent 18 preferred to remove item 29 (*‘Als ik mij haast of sneller loop moet ik stoppen om langzamer lopen. Dat is weer hetzelfde in mijn optiek....Dus deze zal je verwijderen.’*). Respondent 7 preferred to remove item 32 (*‘Als ik mij haast of snel loop, het beste verwijderen dacht ik. Want hier zeggen zij allemaal wat ik niet meer kan.’*). It is not clear why respondent 20 did not fill in the item.

Item 30: *Taken zoals het huishoudelijk werk kosten veel tijd, of ik moet stoppen om uit te rusten.*

Waar Niet waar

Three respondents (R3, R19 & R20) had comments on item 30 and two other respondents (R8 & R16) did not fill in the item. Respondent 19 explained that the item did not apply to her because she got home care (*‘Dit is op mij niet van toepassing want ik heb thuiszorg.’*). Respondent 3 complained that the term ‘housework’ (*‘huishoudelijk werk’*) is

too general and that housework includes impossible tasks for her like vacuum cleaning and doable jobs like window cleaning. She suggested explaining the term ‘housework’ more clearly (*‘Die moeten zij eigenlijk ook wel beter uitleggen.’*).

Respondent 20 had a comment on the response choices of item 30. She wanted a third response choice ‘once in a while’ (*‘Oh, dat is weer zo een vraag en daar heb je allen waar en niet waar. Ja, je kunt daar niets zeggen van af en toe’*). There is no observation why respondent 16 did not fill in item 30. Respondent 8 did not fill in item 30, because she was not able to do housework anymore (*‘Dat doe ik niet meer.’*).

Item 31: *Als ik een trap opga moet ik dat langzaam doen of stoppen onderweg.*

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

No respondents commented on item 31 and one respondent (R8) did not fill in item 31. Respondent 8 said that she did not fill in item 31, because she did not walk up the stairs anymore (*‘Als ik een trap opga, dat doe ik dus niet een trap.’*).

Item 32: *Als ik mij haast of snel loop, moet ik stoppen of langzamer lopen.*

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Four respondents (R7, R13, R18 & R20) had trouble filling in item 32. Respondent 13 thought that ‘I have to stop or slow down’ (*‘Moet ik stoppen of langzamer lopen.’*) is exaggerated and that ‘I have to slow’ down is sufficient (*‘Ik denk dat je stoppen weg kun laten, gewoon langzaam lopen.’*). The comments of respondents 7 and 18 were already reported in the results of item 29.

Respondent 20 was not content with the response choices of the item. She suggested to create a third response choice in between ‘true’ and ‘not true’. (*‘Dat is ook gewoon zo, maar je hebt geen tussenweg. Daar hadden zij nog wat tussen kunnen doen.’*)

Item 33: *Mijn ademhalingsproblemen maken het moeilijk om dingen te doen zoals een helling oplopen, dingen de trap opdragen, dansen, bowlen, golf spelen, of licht tuinwerk zoals wieden.*

Waar Niet waar

Six respondents (R3, R5, R10, R17, R18 & R20) had comments on item 33. Respondents 3, 5, 10, 17 and 20 were all discontent with the fact that so many different activities were assembled in one question. They had different opinions about how to solve the problem. Respondents 10, 17 and 20 simply wanted to divide the activities into several questions (*'Ja, die zou ik opsplitsen.'*). Respondent 18 thought that item 33 and item 34 are the same and wanted to unite them to one item (*'Dus, betekent dat u een vraag daarvan wilt maken?... G: Ja'*). Respondents 3 and 5 wanted to mix the activities in the item with new activities and create new items with the categories of sport, housework or heavy physical activities (*'En dan zou je een stukje sport er in kunnen zetten. En dan zou je daar dansen, bowlen en golf spelen en bijvoorbeeld wandelen en fietsen en zo kunnen inzetten.'*).

Furthermore, respondent 20 had a comment about the response choices of question 33. She suggested adding a third response option stating that the respondent did not have problems with the activities the whole time (*'Daar heb je mogelijkheid nodig, dat het niet altijd is. Mensen die hebben niet altijd daar last van en dat mis ik hier een beetje.'*).

Item 34: *Mijn ademhalingsproblemen maken het moeilijk om dingen te doen zoals zware dingen dragen, de tuin ompsitten of sneeuw ruimen, joggen of snel lopen (8 km per uur), tennissen of zwemmen*

Waar Niet waar

Seven respondents (R1, R2, R5, R10, R17, R18 & R20) had trouble filling in item 34 and one respondent (R3) had a comment and did not fill in the item. Respondent 1 thought that the activities should be divided in a different way and that 'swimming' (*'zwemmen'*) should not be included in the question, because it is a relaxing activity. Respondent 2 explained that the weather is of influence, because activities like 'snow shoveling' are activities that you will have to perform outside when it is cold and wet and this has negative

influence on your COPD (*'De tuin ompsitten dat doe je als het goed weer is. Maar sneeuw ruimen doe je als het buiten vies nat en koud is.'*). Respondent 5 and 3 wanted to create new categories of activities like with item 33. Respondents 10 and 20 suggested that the activities should be divided in a different way (*'Daar moeten zij meerdere vragen van maken. Dat zijn zo veel verschillende dingen, dat hoort niet in een vraag'*). Respondent 17 commented that there are activities in the item that she is still capable of and that there are others than she could not do anymore (*'Tuin spitten dat kun je dan nog best wel. Joggen dat kun je niet, vanwege je conditie.'*). Respondent 18 said that the two items are nearly the same and they could be merged into one item.

General Comment on items 27 to 34:

Dit zijn vragen over hoe uw activiteiten beïnvloed kunnen worden door uw ademhalingsproblemen.

Kruist u alstublieft bij elke bewering het hokje aan dat op u van toepassing is door uw ademhalingsproblemen:

Five respondents (R2, R7, R12, R14 & R20) had general comments on items 27 to 34. Respondent 7 stated that the questions asked in this section are not applicable to her, because she is already in a more severe stadium of COPD and is not capable of doing any of these activities (*'Dat zijn die vragen die komen voor mij helemaal niet meer in aanmerking.'*). Respondent 12 explained that he had more problems with the activities of question 12 in the winter and when it is rainy outside (*'Winterdagen meer last.'*). Respondent 14 explained that 'sex' is an important aspect of quality of life and that she was missing a question about 'sex' in this section (*'Als je daar seks wilt hebben. Dat is wel iets wat in het normale leven heel belangrijk is'*).

Respondent 2 and 20 were not content with the response choices. Respondent 2 said that he was missing the response choice 'sometimes' (*'soms'*) for some of the items (*'Misschien kun daar ook een soms tussen staan of zo. Sommige vragen'*). Respondent 20 stated that it would be better to have more alternatives (response choices) to choose from (*'Daar heb je veel meer keuze. Dat lijkt mij veel mooier.'*).

Short summary of the activity subscale:

Items 29, 32, 33 and 34 of the activity subscale were causing major problems for the respondents. Items 29 and 32 were highly correlated $r = 1.00$ and some respondents stated that one of the two should be removed. Items 33 and 34 also seem to be correlated. Respondent struggled with the high amount of activities used in the two items. The other items of the activity subscale produced only minor problems. Additionally, respondents had problems with the dichotomous response format.

3.4.3 Results of the Impact Scale of the SGRQ- C

Item 8: *Hoe zou u de klachten van uw ademhalingsproblemen omschrijven?*

Wilt u a.u.b. één hokje aankruisen:

Het bezorgt mij een hoop problemen of is het grootste probleem dat ik heb a

Het geeft mij een paar problemen b

Het geeft mij geen problemen c

Five respondents (R5, R8, R11, R12 & R13) had comments on or problems filling in item 8. Respondent 5 explained that she wanted a case distinction based on the time that she has a chest infection (*'luchtweginfectie'*) and the time that she has none, because during a chest infection she had major problems and in between none (*'Het geeft mij geen enkele problemen zolang ik geen luchtweginfectie heb. En het geeft een paar problemen wanneer u hem wel hebt.'*). Respondent 8 wanted a better description of the problems (*'Het bezorgt mij een hoop problemen. Maar daar staat niet bij wat voor problemen.'*). Respondent 11 criticized that it was impossible to answer the question in an objective way, because everybody made his own subjective problems and the answer is only a snapshot (*'momentopname'*) of the problems that the patient had. Respondent 13 wanted the term 'restriction of freedom' (*'vrijheidsbeperkingen'*) to be included in the question. Respondent 12 stated that the answers had no link to the question (*'Maar die antwoorden die u daarop krijgt, die sluiten niet mooi op, naar die vraag.'*).

Instructions items 14 to 19:

Vragen over uw hoest en kortademigheid.

Kruist u alstublieft bij elke bewering het hokje aan dat momenteel? of, de afgelopen dagen? het meest op u van toepassing is:

Item 14: Mijn hoesten is pijnlijk.

Waar

Niet waar

One respondent (R17) had a comment on item 14 and another respondent (R3) did not fill in the item. Respondent 17 suggested changing the question to, 'When does my cough hurt' ('*Wanneer is mijn hoesten pijnlijk.*'). Respondent 3 did not fill in item 14 because he thought that he only should fill in items when he had problems with the activity described in the item.

Item 15: Door mijn hoesten raak ik vermoeid.

Waar

Niet waar

One respondent (R3) did not fill in item 15. Respondent 3 did not fill in item 15 because he thought that he only should fill in items when he had trouble with the activity described in the item.

Item 16: Ik ben kortademig wanneer ik praat.

Waar

Niet waar

Two respondents (R14 & R18) had comments on item 15 and one respondent (R3) did not fill in the item. Respondent 14 stated that the intensity of the conversation is of influence on the breathlessness. She only got short of breath when she was in an intensive conversation ('*Als zo ben ik niet kortademig, maar misschien als je intensieve gesprekken moet voeren.*')

Respondent 18 explained that the duration of the conversation is of influence on his breathlessness. (*'Ik ben kortademig wanneer ik praat, ja hangt af van hoelang je praat'*).

Respondent 3 did not fill in item n 16 for the same reason he did not fill in item 14 and 15.

Item 17: *Ik ben kortademig wanneer ik mij voorover buig.*

Waar

Niet waar

One respondent (R7) had problems filling in item 17, one respondent (R3) did not fill in the item and one respondent (R11) had a comment and did not fill in the item. Respondent 17 said that 'bending over' (*'vooroverbuigen'*) is not explained properly. It depends on the period or amount of time that you will have to bend over. Respondent 11 stated that she is avoiding bending over when she is dizzy (*'benauwd'*) and that is why she did not want to fill in the item (*'Kijk als ik benauwd ben dan buig ik mij sowieso niet voorover.'*). Respondent 3 did not fill in item 17 because of the same reasons he did not fill in the items before.

Item 18: *Mijn hoesten of ademhalingsproblemen verstoren mijn slaap.*

Waar

Niet waar

One respondent (R8) had a comment on item 18 and one respondent (R3) did not fill in item 18. Respondent 8 explained that the item should be directed at the time period when somebody has problems with cough disturbing his sleep. The questions are only concerned with what was going on the last days and that this should be changed (*'Dat is wel waar als ik het heb, maar dit gaat allemaal over het moment.'*). Respondent 3 did not fill in item 18 because of the same reasons he did not fill in the items before.

Item 19: *Ik raak snel uitgeput.*

Waar

Niet waar

One respondent (R17) commented item 19. Respondent 17 wanted to replace the term ‘exhausted’ (‘uitgeput’) with the term ‘tired’ (‘moe’). She did not explain why she thought that ‘tired’ is more appropriate.

General Comments on items 14 to 19 & the instructions:

Vragen over uw hoest en kortademigheid.

Kruist u alstublieft bij elke bewering het hokje aan dat momenteel? of, de afgelopen dagen? het meest op u van toepassing is:

Four respondents (R1, R5, R7 & R12) had general comments on items 14 to 19. Respondent 1 wanted to add an item about ‘stress’ in this section (‘*Ik zou hier bijzetten, stress.*’). Respondent 5 had trouble filling in the items because of the time period (‘*momenteel of afgelopen dagen*’) chosen in the instructions of the question (‘*Als ik het alleen zou moeten doen, ik omschrijf het nu als ik het alleen zou doen dan zou ik ook niet waar invullen maar dan zou ik denken van doe ik het wel goed of doe ik het niet goed.*’)

Respondent 7 stated that the response choices ‘true’ and ‘not true’ are too black and white (‘*zwart wit*’) and that he missed a middle course (‘*tussenweg*’) between the two. Respondent 12 asked for a third response option ‘sometimes’ (‘*soms*’) to fill in the items (‘*Je hebt A, B maar daar moet eigenlijk A, B, C zijn, die zijn waar, niet waar, soms.*’).

Instructions items 20 to 26:

Vragen over andere gevolgen die uw ademhalingsproblemen voor u kunnen hebben.

Kruist u alstublieft bij elke bewering het hokje aan dat deze dagen het meest op u van toepassing is.

Item 20: In het openbaar brengen mijn hoesten of ademhalingsproblemen mij in verlegenheid.

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Three respondents (R1, R12 & R18) had comments on item 20. Respondent 18 criticized that item 20 and item 21 are too similar and that he wanted to remove one of the

two items (*'Nee, omdat het hetzelfde vraagt, het wordt alleen anders beschreven....Ja, de andere gewoon weglaten.'*). It was not possible to identify which of the two items he wanted to remove.

Respondent 1 and respondent 12 wanted to have a third response choice 'sometimes' (*'soms'*), because they did not feel embarrassed by their cough or breathing in public all the time (*'Dus daar moet een antwoordmogelijkheid nog daarbij. Soms, want (..) als je de verhaal verteld en ik kom er altijd met het hoesten tussendoor is dat irritant.'*).

Item 21: *Mijn ademhalingsproblemen zijn lastig voor mijn familie, vrienden of buren.*

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Four respondents (R7, R12, R14 & R18) had comments on item 31 and one respondent (R15) did not fill in the item. Respondent 7 found it difficult to fill in the item because the different groups described in the questions (*'familie vrienden of buren'*) had different attitudes towards her disease. Respondent 18's comment is already discussed in the results of item 20. Respondent 14 did not understand the goal of the question (*'Dat moet je beter omschrijven wat bedoel je daarmee. Ik weet niet wat je daarmee bedoelt.'*).

Respondent 15 did not fill in the item because he said that he did not know if his chest trouble is a nuisance to his family, friends or neighbors (*'Mijn ademhalingsproblemen zijn lastig voor mijn familie, vrienden of buren, nou dat weet ik niet.'*). Respondent 12 wanted 'sometimes' (*'soms'*) as a third response choice.

Item 22: *Ik word bang of raak in paniek als ik niet genoeg adem kan krijgen.*

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Three respondents (R1, R13 & R19) had trouble to fill in item 22. Respondent 13 just stated that the sentence has to be changed (*'Ja en nee. De stelling moet anders'*), but he did not make any suggestions. Respondent 1 and 19 asked for a third response choice

‘sometimes’ (‘soms’) (*‘Ik word bang of raak in paniek als ik niet genoeg adem krijg. (..) Twijfelgeval. (..) Soms wel, soms niet.’*).

Item 23: ***Ik voel dat ik mijn ademhalingsproblemen niet onder controle heb.***

Waar

Niet waar

One respondent (R19) had a comment on item 23. Respondent 19 asked for a middle course between ‘true’ and ‘not true’ (*‘Daar moet er weer een tussenweg komen van waar en niet waar.’*).

Item 24: ***Ik ben zwak of invalide geworden door mijn ademhalingsproblemen.***

Waar

Niet waar

Four respondents (R1, R7, R13 & R19) had comments on item 24. First respondent 1 wanted to remove the whole question (*‘Nee. Ik zou die zin helemaal weg halen.’*). And afterwards he wanted to replace the item with the exact same text. Respondent 7 thought that the item was poorly arranged, because her weakness and invalidity are not only caused by her breathing problems. Other things like comorbidity or age also have influence on these factors. (*‘Dat is gedeeltelijk, omdat het mijn zwak en invalide niet alleen door mijn ademhalingsproblemen zijn gekomen. Dat heeft meer en meer factoren, dat zeg ik’*). Respondents 13 and 19 stated that the term ‘invalid’ is too strong and it should be changed (*‘Zwak en invalide geworden, komt hard aan voor de mensen.’*).

Item 25: ***Lichamelijke oefening is niet veilig voor mij.***

Waar

Niet waar

Seven respondents (R2, R3, R14, R16, R17, R18 & R20) had comments on item 25 and two respondents (R3 & R11) did not fill in the item. Respondent 2, 14, 16, 17, 18 and 20 were not able to fill in item 25; because the term ‘physical exercise’ (*‘lichamelijke oefening’*) was not clear to them. They did not understand which activities were included in ‘physical exercise’ (*‘Lichamelijke oefening is niet veilig voor mij. Wat bedoelen zij daar dan mee.’*). Furthermore respondent 3 suggested replacing the item with an open question like ‘which activities can you still perform’ (*‘De vraag zou wel zijn welke. Ja. En dan komt de antwoord automatisch.’*). And respondent 17 wanted to add the questions; ‘Do you perform physical exercise supervised or alone’ (*‘Doe je dit onder begeleiding of alleen.’*). Respondents 3 and 11 also did not fill in the item because they also did not understand what was meant by ‘physical exercise’ (*‘Lichamelijke oefening dat staat er niet bij.’*).

Item 26: *Alles lijkt mij een te grote inspanning.*

Waar

Niet waar

Two respondents (R1 & R14) had comments on item 36 and one respondent (R3) did not fill in the item. Respondent 14 wanted to replace the word ‘seem’ (*‘lijkt’*) with the word ‘is’ (*‘is’*) (*‘Lijkt gewoon, maar is gewoon.’*). Respondent 1 wanted a third response option ‘sometimes’ (*‘soms’*) (*‘Ik wil er ook weer soms daarbij willen hebben.’*). Respondent 3 did not fill in the item because according to him the question was unclear (*‘Dat is ook geen duidelijke vraagstelling.’*).

General Comments on items 20 to 26:

*Vragen over andere gevolgen die uw ademhalingsproblemen voor u kunnen hebben.
Kruist u alstublieft bij elke bewering het hokje aan dat deze dagen het meest op u van toepassing is.*

Five respondents (R1, R5, R6, R8 & R19) had general comments on items 20 to 26. Respondent 1 and 5 wanted to change the time period used in the instruction of the question. Respondent 1 wanted to replace ‘these days’ (*‘deze dagen’*) with ‘this month’ or ‘last months’ (*‘Deze dagen, kan weer deze maand, of maanden’*). Respondent 5 wanted to change it to ‘the

days of your respiratory problems' (*'De dagen van u ademhalingsproblemen.'*). Respondent 7 was not sure which time period was used in the items (*'Dat is toch een vraag over dit jaar?'*). Additionally he wanted to replace the time period 'these days' with 'last month' (*'Langer periode want voor mij, ik ben heel lang heel slecht geweest.'*). Respondent 19 was also not content about the time period they used in the question and wanted more response choices. Respondent 8 asked for a third response choice, he wanted the response choice 'when your are sick' (*'Als je ziek bent.'*).

Instructions items 35 to 39:

We willen graag weten hoe uw ademhalingsproblemen gewoonlijk uw dagelijks leven beïnvloeden.

Kruist u alstublieft bij elke bewering het hokje aan dat op u van toepassing is door uw ademhalingsproblemen:

Item 35: Ik kan niet aan sport of spel doen.

Waar

Niet waar

Ten respondents (R1, R2, R6, R7, R11, R12, R13, R14, R17 & R18) had comments on item 35 and two respondents (R3 & R11) did not fill in the item. Respondents 2, 6, 7, 12, 13 and 14 found it difficult to fill in the item because of the discrepancy between 'sports' and 'games'. Most of them thought that they are still able to play board games like 'monopoly' but not able to participate in physical sport games (*'Daar heb je dat weer sport en spel. Spel kan wel maar sport niet.'*). Respondent 11 wanted to change the question to 'how much can you still participate in sports and games' (*'Hoeveel kunt U nog zo aan spel en sport doen.'*). Respondent 17 wanted to change the question; asking respondents if they could still participate in sport, reasonable, moderate or light. And respondent 18 wanted to remove 'games' from the question, because he expected that COPD patient cannot participate in any kind of sport. That was why he wanted to change the question to 'I cannot do sports because...' (*'Ik kan niet aan sport doen want...'*). Respondent 1 wanted a third response choice 'sometimes' (*'soms'*). Respondents 3 and 11 also did not want to fill in the question because of the discrepancy between 'sports' and 'games'.

Item 36: Ik kan niet uitgaan voor amusement of ontspanning.

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Two respondents (R1 & R9) had comments or problems filling in item 36 and one respondent (R3) did not fill in the item. Respondent 9 had problems filling in item 36 as she said that she had no problems to go out for entertainment or recreation, but filled 'true' in. Respondent 9 had general problems to fill in the questionnaire. Respondent 1 stated that he wanted a third response choice 'sometimes' ('soms') ('Ik wil er ook soms weer bij hebben.'). Respondent 3 did not fill in the item, because the concepts of 'entertainment' and 'recreation' were not clear to him ('Kijk want amusement of ontspanning. Ontspanning. Een spel of wat anders?').

Item 37: Ik kan niet het huis uitgaan om boodschappen te doen.

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Three respondents (R3, R14 & R18) had comments filling in item 37. Respondents 3 and 18 said the question had to be changed to 'I cannot go out of the house to do the shopping with the help of my mobility scooter or car' ('...met hulp van een scootermobiel. Of de auto.'). Respondent 14 wanted to change the question to 'can you go shopping by yourself' ('Kun je zelfstandig boodschappen doen?'). All three respondents stated that they needed support for going shopping because it is a heavy task for them.

Item 38: Ik kan geen huishoudelijk werk doen.

Waar	Niet waar
<input type="checkbox"/>	<input type="checkbox"/>

Three respondents (R1, R15 & R17) had comments on item 38 and one respondent (R3) did not fill in the item. Respondents 1, 15 and 17 all thought that 'housework' is a broad term including activities that they still can perform and some heavy task that they are unable

to perform (*'Huiswerk doe ik normaal zelf, alleen stofzuigen daar heb ik iemand voor.'*). All three of them said that 'vacuum cleaning' is a heavy task that they could not perform anymore. Respondent 3 did not fill in the item, because for him it is a multiple-choice question (*'Ik kan geen huishoudelijke werk doen, ja dat is ook weer een meerkeuze vraag.'*).

Item 39: *Ik kan niet ver van mijn bed of stoel komen.*

Waar

Niet waar

Four respondents (R1, R5, R13 & R20) had comments on item 39 and one respondent (R15) did not fill in the item. Respondent 1 was not content with the item, he wanted to change the item to 'When you wake up in the morning, are you able to move far from your bed' (*'Hoe is het als je morgens waker bent. Kunt u dan ver, kunt u dan uit de bed komen'*). Respondent 5 wanted to change the item to 'I cannot get out of my bed or get out of my seat' (*'Ik kan niet goed uit mijn bed komen of uit mijn stoel komen.'*). Respondent 13 was not sure about the exact meaning of the word 'far' (*'Ver, ja wat is ver.'*). Respondent 20 said that item 39 was an item that was more suited for COPD patients in the last stadium of the disease (*'Ik kan niet ver van mijn bed of stoel komen, nee dat is echt voor mensen die het heel erg hebben.'*). And respondent 15 did not fill in the item, because he wanted a clearer indication of the distance and he thought that this was a strange question (*'Ja, wat is niet ver, 20 meter, 30 meter, 100 meter?'*).

General Comments on items 35 to 39 & the instructions:

We willen graag weten hoe uw ademhalingsproblemen gewoonlijk uw dagelijks leven beïnvloeden.

Kruist u alstublieft bij elke bewering het hokje aan dat op u van toepassing is door uw ademhalingsproblemen:

Three respondents (R2, R5 & R20) had general comments on items 35 to 39. Respondent two missed a question about 'how COPD influence his work experience' (*'Het beroep zeg maar, met je beroep'*). Respondent 5 complained that the statement in the instruction of question 13, 'how your chest trouble usually affects your daily life' does not fit

her situation, because her daily life is not affected by COPD (*'Gewoonlijk beïnvloed is mijn dagelijkse leven niet.'*). Furthermore, respondent 20 stated that the items 35 to 39 are questions for people in the last stadium of the disease (*'Dan zijn dat vragen voor iemand die helemaal niets meer kan'*).

Item 40: Hoe beïnvloeden uw ademhalingsproblemen u?

Het weerhoudt mij er niet van iets te doen dat ik graag zou willen doena

Het weerhoudt mij ervan één of twee dingen te doen die ik graag zou willen doen.. b

Het weerhoudt mij ervan de meeste dingen te doen die ik graag zou willen doenc

Het weerhoudt mij ervan alles te doen wat ik graag zou willen doen d

Four respondents (R1, R12, R13, & R18) had comments or problems filling in item 40 and seven respondents (R3, R4, R8, R9, R15, R17 & R19) did not fill in the item correctly or not at all. Respondent 12 wanted to change the question to 'how motivated are you to do something in addition to your respiratory problems' (*'Hoe gemotiveerd bent u nog (.) om naast u ademhalingsproblemen om iets te doen.'*). Furthermore there was a general problem concerning nearly all respondents to switch their way of filling in an item from dichotomous (true/ not true) to multiple choice questions. The respondents clearly needed more time to fill in item 40.

Respondents 1, 12, 13, and 18 were not content with the response options, according to them the response choices were too similar (*'Dat lijkt alles een beetje op elkaar, die andere vragen zijn een beetje meer to the point.'*). Respondent 3, 8 and 17 did not fill in the item because according to them the item was strange (*'Vind ik een beetje rare vraag.'*) Respondents 4, 8 and 15 completed the question incorrectly (more than one cross). Additionally, respondent 19 did not fill in the item at all, because she did not understand the question.

Short summary of the Impact subscale:

Respondents had major problems to complete items 25, 35 and 40 of the Impact subscale. Respondents had major problems with the interpretation of the term 'physical exercise' used in item 25 and they had problems with the distinction between the 'sports' and 'games' in item 35. Furthermore, respondents had major problems to fill item 40 correctly. Item 39 was completed with 'not true' by every respondent. The remaining items of the Impact subscale only caused minor problems. Additionally, respondents frequently requested a third response option while completing dichotomous items.

4. Discussion

In the following section, the results are discussed in context of the existing knowledge on HRQL of COPD patients, the SGRQ and SGRQ-C, followed by suggestions for possible improvements for certain items. For a better overview, the improvement section is divided into the three subscales of the SGRQ-C (Symptoms, Activity and Impact). In § 4.4, the usability of the TSTI method will be discussed, followed by the limitations of the study in § 4.5.

4.1 Discussion of results in the context of previous studies

Earlier research showed that the SGRQ is a valid and reliable measurement instrument in different languages (Liang et al., 2008; El Rhazi et al.2006; Engstrom, Persson, Larsson & Sullivan, 1998; Ferrer et al., 1996; Yu, Scudds & Scudds, 2004; Rutten- van Molken, Roos & Van Noord, 1999; Karpinski, 2005). However, only little information existed about how patients perceive the questionnaire. The aim of this study was to examine the experiences of COPD patients while completing the SGRQ-C. We found that the respondents were generally content with the questionnaire; they only had problems with some response choices as well as with terminology used in some items. These rather small problems could have been avoided by using the TSTI method during the development of the SGRQ and SGRQ-C.

There were only few similarities between problems found in this study and problems found in previous SGRQ studies. A possible explanation is that the TSTI evaluates the respondent's perception of each item in a qualitative way whereas previous studies mostly concentrated on psychometric weaknesses of the SGRQ results. As stated in the introduction, the TSTI makes it possible to find problems with the completion of the items that were not observable with quantitative measures (Hak, van der Veer & Jansen, 2008).

For instance, several authors proposed that items 5 and 7 are more suitable for evaluating difficulties with asthma rather than difficulties with COPD (Rutten-van Mólken, Roos & Van Noord, 1999; Karpinski, 2005). The respondents in this study reported no problems with item 7. Problems with item 5 were concerning the time period chosen and the amount of attacks used in the responses. In conclusion, item 5 and 7 both seemed to be suitable for COPD patients.

Paap et al. (2013) showed that the SGRQ could be shortened from 50 to 31 items without any substantial impact on the reliability. Seven of the 19 items were already removed during the development of the SGRQ-C. Ten items only caused minor problems for the respondents in this study. Consequently, the results of the two studies complement each other and demonstrate that the use of the TSTI method enables us to identify problems with the completion of the items that were not observable without. Items 5 and 35 of the SGRQ-C were the only items which could be identified as problematic in both our and their study.

Our results could not replicate the high reliability which was found in previous validation studies of the SGRQ (Karpinski, 2005). Due to the high number of missing values, it was only possible to calculate the reliability of the Symptoms subscale ($\lambda^2 = 0.72$). Without the high amount of missing values in the other two subscales, we might have found values indicating a sufficient reliability as well for the other two subscales since the Symptoms scale was found to have the lowest reliability values of the three subscales in previous studies (Karpinski, 2005).

This study had to deal with more missing values than any other SGRQ study in the literature. The highest amount of missing values in the literature was found in a Swedish study when 7 of 131 patients were not able to complete the SGRQ (Stállberg et al., 2009). The high amount of missing values in this study appeared less problematic after analyzing their sources. Respondent 3 and item 40 were the main reasons for the high amount of missing values. Respondent 3 produced almost half of all missing values, mostly because he

did not carefully read the instructions of questions 9 and 10 and thought he only had to complete items if he had problems with an activity. For future use of the SGRQ-C, it is essential to instruct respondents to read the instructions of the questions carefully in order to avoid missing data.

Item 40 produced many missing values as the respondents had problems completing a polytomous item after they completed 31 dichotomous items in a row. Besides, it was a difficult question at the end of a long questionnaire and respondents had problems to differentiate the response choices from each other because according to them they were too similar. It might have been a solution to place the item at the beginning of the questionnaire or to remove it. Additionally, the presence of the interviewer may have increased the number of missing values because respondents had the possibility to explain why they did not fill in an item to the person evaluating their questionnaire. Respondents might have been more likely to choose one of the response choices of a problematic item in a normal self-completion situation. Anyway, the CAT will not have problems with missing values, because the only possible way to continue with the next item is to answer the previous one.

As stated in the introduction, former usage of the TSTI for evaluation of questionnaires showed that most of the problems that were observed originated from mismatches between the 'theory' underlying a question and the respondent's real life (Hak, van der Veer & Jansen, 2008). The same phenomenon was observed in this study. Some of the respondents had individual problems filling in the questionnaire. For example, respondent 16 explained that he could not fill in some of the items because he did not know if he was able to perform the activities. He had an attack of chest trouble ten days before the interview and had not left the hospital bed since. He explained that before the attack he was only diagnosed with asthma (*'Ik heb astma gehad. Maar dat heeft nou overgeblazen naar COPD. COPD vier, dus. Dit kan ik dus nou niet zeggen.'*). The fact that the respondent was diagnosed with COPD GOLD IV makes his explanation disputable. Respondent 9 had problems with the understanding of the questionnaire. The respondent was constantly looking for the affirmation of her daughter while filling in the questionnaire and had problems reading some of the items. Nevertheless, it was important to see which problems these patients encounter as every patient has to be able to fill in the questionnaire.

Weather was a topic that was often raised when filling in the first part of the questionnaire. Patients stated that the weather had influence on COPD symptoms (items 1-7)

as well on the activities in items 10 and 34. They explained that their COPD caused more problems when it was cold and moist outside. Items about the influence of weather (humidity, temperature) on the patient's symptoms should be considered in the development of the CAT, as weather influencing the well-being of COPD patients was also discussed in the literature (Ferrari et al., 2012). An example item related to weather could be; 'Do your symptoms get worse when it is rainy outside?'

Furthermore, respondent missed some activities that were important for their QoL. They missed items about 'riding a bike', 'sex' and 'stress'. A bike is a very common means of transport in the Netherlands; it helps people to remain mobile and therefore increases patient's quality of life. Sex and stress also influence people's quality of life (Ventegod, 1998; Bovier, Chamot & Perneger, 2004). I recommend considering all three terms for the development of the CAT.

4.2 Discussion of the response formats

The dichotomous and multiple choice items used in the SGRQ-C were mostly well received by the respondents. Nevertheless, both formats created their own minor problems. Respondents often asked for a third response option between the two response choices 'true' and 'not true' (dichotomous items), like 'sometimes'. This was an understandable request as each respondent may have had their own explanation why they were not sure whether to fill in 'true' or 'not true'. Nevertheless, using 'sometimes' as a third response option is problematic, because it is a broad term that can cause a lot of misinterpretation. Response choices like 'two times per week' are clearly defined for every respondent. 'Sometimes' can be interpreted as 'ten times per week' by one respondent and as 'one time per week' by another respondent. It would be impossible to give 'sometimes' an empirically derived weight. I can think of three possible explanations why respondents asked for the response choice 'sometimes' in so many cases. First of all the social desirability bias, as people who filled in a self-report measure like the SGRQ-C tried to answer items in a manner that would be viewed as favorable by others especially in a face-to-face interview situation like the TSTI method (Arnold & Feldman, 1981). Respondents did not want to create a negative image of themselves in front of the interviewer by admitting that they could not perform a certain activity. They tried to present themselves in a better condition than they were in by saying 'I cannot perform this activity but sometimes I can'. For example, respondent 14 who had COPD GOLD IV came to the interview sitting in a wheelchair because she was not able to

walk. Nevertheless, she asked for a response choice 'sometimes' while filling in item 14 ('Walking outside on the level'). The second explanation is the 'bias in subject information processing'. Like already explained in the methods section, one problem of the think aloud method was that respondents invested clearly more amount of mental effort to answer the questions in the think aloud procedure than they would normally do while completing a questionnaire (Willis, 1999). It made them overthink an activity of a certain item until they remember a situation when they were able or unable to perform the activity. Like respondent 6 stated when he talked about the response choices of question nine ('*Dat moet ik hardop praten en dan moet ik wat nadenken.*'). A third explanation is that COPD patients could not decide between the two response options because COPD has a fluctuating character. Patients have much trouble on one day but feel much better the next one. Therefore, the dichotomous choice format might not be the right response format. I recommend using a multiple choice format for the 31 item that were using a dichotomous response format before. The five possible response choices would be: (1) every day of the week ('*Elke dag van de week*'); (2) most days a week ('*De meeste dagen van de week*'); (3) several days a week ('*meerdere dagen van de week*'); (4) only with chest infection ('*alleen bij een luchtweginfectie*'); (5) not at all ('*helemaal niet*').

The multiple choice response formats used for items 1 to 6, 8 and 40 only caused problems for items 5 and 40. Item 5 used the reporting period of 'one year'. For that reason respondents thought that three attacks of chest trouble per year did not represent their amount of attacks because they had an amount of attacks which was significantly higher. The problems with the response choices of item 40 were already discussed above.

Another response choice that might be considered for the CAT is 'I am not capable of doing this activity (on my own)' ('*Ik voer de activiteit niet meer zelf uit*'). Respondents did not know if they were able to perform certain activities, because in they got help with the activity or avoided the activity. For example, respondent 8 said that she did not fill in item 31, because she did not walk up the stairs anymore. Respondent 19 thought that it was difficult to complete items 9 to 13 because she was not capable of doing many things on her own and got daily support by home care staff.

4.3 Suggestions for possible improvements for Items

4.3.1 Suggestions for possible improvements for Symptom Items

There are only two suggestions for possible improvement for the Symptoms subscale. Adding 'every day' ('*elke dag*') as an extra response option for items 1 to 4 may have led to fewer problems with items in the Symptoms subscale. Especially patients who suffered from COPD GOLD IV experienced a higher frequency of symptoms than 'most days a week'. Additionally, reducing the time period used in item 5 from 'last year' to 'last month', in order to achieve an easier recall of the amount of attacks of chest trouble.

4.3.2 Suggestions for possible improvements for Activity Items

In the activity subscale items 33 and 34, which seemed to correlate for most patients ($r = 0.65$), caused problems for many respondents. Respondents found it difficult to answer the items with 'true' or 'not true', because the question included activities that they were not able to do anymore but also activities which they could still perform. A suggestion for improvement that might have decreased the number of problems with these two items is to divide the activities into several items and leave out the sport activities (bowling, playing golf, tennis and jogging) and walking up a hill. Sport activities were already covered by item 35 and walking up a hill was covered by item 13.

Furthermore two respondents stated that items 29 and 32 were exactly the same which was supported by the inter-item correlation of $r = 1.00$. I recommend removing one of the items from the questionnaire, because it is dispensable.

4.3.3 Suggestions for possible improvements for Impact Items

Items 25 and 35 were two of the items in the questionnaire that caused the most problems. Respondents had major problems with the interpretation of the terms 'physical exercise' ('*lichamelijke oefening*') and 'sports or games' ('*sport of spel*'). Respondents did not understand which exercises were included in 'physical exercise' (item 25) and which were not. I recommend removing the item from the questionnaire, because 'physical exercise' is a broad term that includes too many different activities. Furthermore, the term 'physical exercise' is already covered by other terms used in items of the impact and activity subscale like sport, games, playing golf, dancing, housework and light garden work.

The distinction between 'sports' and 'games' was a major problem for respondents. They explained that they could still participate in games but had problems with sports. Respondents associated board games like 'Monopoly' with the term 'games'. These kinds of

games do not require the physical strength needed in physically active sports like football or volleyball. None of the respondents' recommendations to improve the item could be put into practice. Therefore, it might have been the easiest solution to split the item into two items; 'I cannot play sports' and 'I cannot play board game'.

All 20 respondent completed item 39 with 'not true'. Even the ten COPD GOLD IV patients thought that they were able to move far from their bed of chair. Therefore, I recommend removing the item because it cannot discriminate between respondents. See *Appendix E* for an overview on the most important suggestions for improvements.

4.4 Usability of the TSTI

Overall, the TSTI appeared to be an effective method in this study. The usage of the think aloud method and the cognitive interview clearly helped getting the experience of patients while filling in the SGRQ-C and thereby analyze the patients perspective in detail.

The manual of the TSTI gave clear instructions for the interview and made it possible to perform the procedure properly (Hak, van der Veer & Jansen, 2004). The interviewer got more familiar with the method through the completion of several interviews and two feedback moments with more experienced interviewers.

Nevertheless, there were also problems resulting from the use of the TSTI. First of all the TSTI is a very time consuming method. Two of the interviews lasted more than one hour (respondents 18 & 20). Especially inpatients, who were in a bad state of health, were getting tired at the end of the interviews. Respondent 15 and 17 explicitly stated that they were tired and could not concentrate anymore (*'Ik kan mij helemaal niet meer concentreren.'*). Their fatigue may have led them to report fewer problems than they otherwise would have. As stated in the results, inpatients reported fewer problems. For future research with the TSTI, it should be recommended to split long questionnaires in two or more parts to reduce the workload on each respondent, if the participants are in a bad health condition.

Additionally, some respondents had difficulties verbalizing their thoughts as this is a very uncommon task ('subject resistance'), like stated in the method section (Willis, 1999). Respondents like respondent 1 were capable of formulating their own thoughts, other respondents like respondent 15 only read the instructions and the questions aloud, but had problems explaining their answers. Nevertheless, this difficulty did not influence the results, because as soon as the respondents encountered a problem with the questionnaire, they were able to formulate their critique verbally. The interviewer should practice the think aloud

procedure with the respondents until he thinks that the respondent is able to perform the procedure, before starting the interview in future research.

4.5 Limitations of the study

The first limitation of the study was the little experience of the researcher who conducted 19 of the 20 interviews as an interviewer. The interviewer trained the procedure with friends and got feedback from two more experienced researchers, but nevertheless he had more problems conducting the first interviews in comparison with the last interviews. He was nervous during the first interviews because he had little experience in conducting an interview. In later interviews, the interviewer got more routine and therefore had more cognitive capacities to concentrate on his nonverbal communication (keep eye contact, sitting straight) and listening skills. However, these problems seemed to have had no influence on the results of the first interviews. A recommendation for further research would be to practice the TSTI method with people who have a similar educational level like the target group of patients and who are not familiar with the think aloud method.

The small amount of participating men and the absence of COPD GOLD I patients had a negative influence on the representativeness of the sample. Only 7 of 20 respondents were men, which do not reflect the male proportion of more than 50% in the Dutch population of COPD patients (Nationaal Kompas Volksgezondheid, 2013). Recruiting respondents in the hospital showed that men were less willing than women to participate in the study. They seemed afraid to participate in a study related to their HRQL. Recruiting more men might have led to more reported problems with items because men reported more problems than women, as stated in the results. COPD GOLD I patients could not be recruited because the majority of this group of patients were still treated by their general practitioner or are unaware that their lung function is abnormal (Jones, 1995; Global Initiative for Obstructive Chronic Lung Disease, 2007). The respondents for this study were recruited exclusively in the MST. However, the SGRQ-C might not be a useful instrument measuring the HRQL of COPD GOLD I patients anyway, as most items of the questionnaire are not applicable to them. As mentioned in the introduction, patients in the first stage of COPD only feel disturbance of physical activity during sports or other intensive physical activities. Essential activities of daily life will not be disturbed until FEV¹ scores fall below 50 percent (Jones, 1995).

5. Conclusions

This study examined what COPD patients experience while completing the SGRQ-C. By using the TSTI we could successfully identify and diagnose the respondents' problems. Overall, respondents were satisfied with the SGRQ-C. Only minor problems were found that might have been avoided by using the TSTI procedure in the development of the questionnaire. The biggest problems found were the understanding and interpretation of specific terminology used in the questionnaire. Terms like 'good days', 'hill', 'physical exercise', 'sports', 'games' and 'housework' were causing issues. The terms should be described concretely or removed from the questionnaire. Furthermore, there were problems with the time period used in the instructions of some questions. Respondents had trouble with reporting periods like 'these days' and 'last year'. The reporting periods should be changed to simplify the recall. Moreover, response choices were also causing negative experience for respondents. Participants asked for a third response option between the two response choices 'true' and 'not true' which are used for the majority of items. They felt unable to explain their current state of well-being by filling in 'true' or 'not true'. Therefore, I recommend using multiple choices items for all items.

Additionally, the results give useful information whether to include items of the SGRQ-C into the item bank of a CAT measuring the quality of life for COPD patients. Overall, all items except for items 25, 32 and 39 have the potential to be included in the CAT, after small adjustments. Furthermore, respondents suggested activities ('riding a bicycle', 'sex' and 'stress') and response choices ('I am not capable of doing this activity (on my own)') that could be included in the CAT.

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Appendix A. The Dutch version of the SGRQ-C

Ademhalingsvragenlijst van het St. George ziekenhuis voor COPD patiënten

(SGRQ-C)

Deze vragenlijst is bedoeld om ons te helpen meer inzicht te krijgen in uw ademhalingsproblemen en hoe deze uw leven beïnvloeden. We gebruiken deze vragenlijst om uit te vinden welke aspecten van uw ziekte u de meeste problemen geven, en niet zozeer wat de artsen en verpleegkundigen denken dat uw problemen zijn.

Lees a.u.b. zorgvuldig de instructies door en indien u iets niet begrijpt kunt u dit vragen. Denkt u a.u.b. niet te lang na over uw antwoord.

Onderzoeksnummer: _____

Datum : ____/____/____ (dd/mm/jj)

Voor u de rest van de vragenlijst invult:

Geef a.u.b., door één hokje aan te kruisen, aan hoe uw gezondheid op dit moment is:

Zeer goed

Goed

Redelijk

Slecht

Zeer slecht

Version: 1st Sept 2005

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continued...

SGRQ-C (Netherlands-Dutch) 16AUG2013 FINAL updated

Ademhalingsvragenlijst van het St. George ziekenhuis DEEL 1

Vragen over hoeveel ademhalingsproblemen u heeft.

Wilt u a.u.b. één hokje aankruisen voor elke vraag

Vraag 1.Ik hoest:

- de meeste dagen v.d. week..... a
meerdere dagen v.d. week b
alleen bij een luchtweginfectie.... c
helemaal niet d

Vraag 2. Ik geef slijm op:

- de meeste dagen v.d. week..... a
meerdere dagen v.d. week b
alleen bij een luchtweginfectie ... c
helemaal niet d

Vraag 3.Ik ben kortademig

- de meeste dagen v.d. week..... a
meerdere dagen v.d. week b
helemaal niet c

Vraag 4.Ik heb last van piepende ademhaling

- de meeste dagen v.d. week..... a
meerdere dagen v.d. week b
een paar dagen v.d. maand..... c
alleen bij een luchtweginfectie ... d
helemaal niet e

Vraag 5. Hoeveel zware of zeer onaangename aanvallen van ademhalingsproblemen had u gedurende het afgelopen jaar?

3 of meer aanvallen a

1 of 2 aanvallen b

Nooit c

Vraag 6. Hoe vaak heeft u goede dagen (met weinig last van ademhalingsproblemen)?

geen a

een paar goede dagen b

de meeste dagen zijn goed c

elke dag is goed..... d

Vraag 7. Als u last heeft van piepen op de borst, is dit dan 's ochtends het ergste?

Nee.....

Ja.....

Ademhalingsvragenlijst van het St. George ziekenhuis DEEL 2

8. Hoe zou u de klachten van uw ademhalingsproblemen omschrijven?

Wilt u a.u.b. één hokje aankruisen:

Het bezorgt mij een hoop problemen of is het grootste probleem dat ik heb.... a

Het geeft mij een paar problemen b

Het geeft mij geen problemen c

9. Vragen over welke activiteiten u normaal gesproken kortademig maken.

Kruist u alstublieft bij elke bewering **het hokje** aan dat **momenteel?** of **, de afgelopen dagen?** het meest op u van toepassing is

	Waar	Niet waar	
Wassen of aankleden	<input type="checkbox"/>	<input type="checkbox"/>	a
Thuis rondlopen.....	<input type="checkbox"/>	<input type="checkbox"/>	b
Buiten lopen op vlak terrein	<input type="checkbox"/>	<input type="checkbox"/>	c
De trap opgaan (één verdieping).....	<input type="checkbox"/>	<input type="checkbox"/>	d
Een helling oplopen	<input type="checkbox"/>	<input type="checkbox"/>	e

Ademhalingsvragenlijst van het St. George ziekenhuis

DEEL 2

10. Vragen over uw hoest en kortademigheid.

Kruist u alstublieft bij elke bewering **het hokje** aan dat **momenteel?** of, **de afgelopen dagen?** het meest op u van toepassing is:

	Waar	Niet waar
Mijn hoesten is pijnlijk	<input type="checkbox"/>	<input type="checkbox"/> a
Door mijn hoesten raak ik vermoeid	<input type="checkbox"/>	<input type="checkbox"/> b
Ik ben kortademig wanneer ik praat	<input type="checkbox"/>	<input type="checkbox"/> c
Ik ben kortademig wanneer ik mij voorover buig	<input type="checkbox"/>	<input type="checkbox"/> d
Mijn hoesten of ademhalingsproblemen verstoren mijn slaap	<input type="checkbox"/>	<input type="checkbox"/> e
Ik raak snel uitgeput	<input type="checkbox"/>	<input type="checkbox"/> f

11. Vragen over andere gevolgen die uw ademhalingsproblemen voor u kunnen hebben.

Kruist u alstublieft bij elke bewering **het hokje** aan dat **deze dagen** het meest op u van toepassing is

	Waar	Niet waar
In het openbaar brengen mijn hoesten of ademhalingsproblemen mij in verlegenheid	<input type="checkbox"/>	<input type="checkbox"/> a
Mijn ademhalingsproblemen zijn lastig voor mijn familie, vrienden of burens	<input type="checkbox"/>	<input type="checkbox"/> b
Ik word bang of raak in paniek als ik niet genoeg adem kan krijgen	<input type="checkbox"/>	<input type="checkbox"/> c
Ik voel dat ik mijn ademhalingsproblemen niet onder controle heb	<input type="checkbox"/>	<input type="checkbox"/> d
Ik ben zwak of invalide geworden door mijn ademhalingsproblemen ...	<input type="checkbox"/>	<input type="checkbox"/> e
Lichamelijke oefening is niet veilig voor mij	<input type="checkbox"/>	<input type="checkbox"/> f
Alles lijkt mij een te grote inspanning	<input type="checkbox"/>	<input type="checkbox"/> g

Ademhalingsvragenlijst van het St. George ziekenhuis DEEL 2

12. Dit zijn vragen over hoe uw activiteiten beïnvloed kunnen worden door uw ademhalingsproblemen.

Kruist u alstublieft bij elke bewering **het hokje** aan dat op u van toepassing is **door uw ademhalingsproblemen**:

	Waar	Niet waar
Ik doe er lang over om mij te wassen of aan te kleden	<input type="checkbox"/>	<input type="checkbox"/> a
Ik kan niet in bad gaan of een douche nemen, of het kost veel tijd	<input type="checkbox"/>	<input type="checkbox"/> b
Ik loop langzamer dan andere mensen, of ik stop om uit te rusten	<input type="checkbox"/>	<input type="checkbox"/> c
Taken zoals het huishoudelijk werk kosten veel tijd, of ik moet stoppen om uit te rusten	<input type="checkbox"/>	<input type="checkbox"/> d
Als ik een trap opga moet ik dat langzaam doen of stoppen onderweg ...	<input type="checkbox"/>	<input type="checkbox"/> e
Als ik mij haast of snel loop, moet ik stoppen of langzamer lopen	<input type="checkbox"/>	<input type="checkbox"/> f
Mijn ademhalingsproblemen maken het moeilijk om dingen te doen zoals een helling oplopen, dingen de trap opdragen, dansen, bowlen, golf spelen, of licht tuinwerk zoals wieden	<input type="checkbox"/>	<input type="checkbox"/> g
Mijn ademhalingsproblemen maken het moeilijk om dingen te doen zoals zware dingen dragen, de tuin omspitten of sneeuw ruimen, joggen of snel lopen (8 km per uur), tennissen of zwemmen.....	<input type="checkbox"/>	<input type="checkbox"/> h

13. We willen graag weten hoe uw ademhalingsproblemen gewoonlijk uw dagelijks leven beïnvloeden.

Kruist u alstublieft bij elke bewering **het hokje** aan dat op u van toepassing is **door uw ademhalingsproblemen**:

	Waar	Niet waar
Ik kan niet aan sport of spel doen	<input type="checkbox"/>	<input type="checkbox"/> a
Ik kan niet uitgaan voor amusement of ontspanning	<input type="checkbox"/>	<input type="checkbox"/> b
Ik kan niet het huis uitgaan om boodschappen te doen	<input type="checkbox"/>	<input type="checkbox"/> c
Ik kan geen huishoudelijk werk doen	<input type="checkbox"/>	<input type="checkbox"/> d
Ik kan niet ver van mijn bed of stoel komen	<input type="checkbox"/>	<input type="checkbox"/> e

Ademhalingsvragenlijst van het St. George ziekenhuis

14. Hoe beïnvloeden uw ademhalingsproblemen u? Wilt u a.u.b. één hokje aankruisen:

Het weerhoudt mij er niet van iets te doen dat ik graag zou willen doen a

Het weerhoudt mij ervan één of twee dingen te doen die ik graag zou willen doen b

Het weerhoudt mij ervan de meeste dingen te doen die ik graag zou willen doen . c

Het weerhoudt mij ervan alles te doen wat ik graag zou willen doen d

Dank u voor het invullen van deze vragenlijst

Voor u eindigt, wilt u a.u.b. nagaan of u alle vragen heeft beantwoord?

Appendix B. Information letter for the patients

TOSTI-studie

Observeren welke ervaringen COPD patiënten maken tijdens het invullen van de SGRQ-C, met hup van de Three Step Test Interview (TSTI).

Mw./ Meneer X
X straat XX
XXXX YY City

17 oktober 2013

Geachte mevrouw/ meneer X,

Hierbij ontvangt u een uitnodiging voor de TOSTI-studie. Bijgevoegd in de envelop zit het toestemmingsformulier van het onderzoek. De afspraak zal plaatsvinden op: **weekdag XX maand 2013 om xx:zz uur.**

Als het interview plaats vind op het ziekenhuis kunt U zich melden bij de balie van de Polikliniek Longgeneeskunde (Poli 10). We vragen u het toestemmingsformulier mee te nemen naar het ziekenhuis.

Indien u met de auto komt, dan kunt u deze parkeren in de parkeergarage bij de ingang aan de Haaksbergerstraat. De parkeerkosten zullen vergoed worden.

Mocht u nog vragen hebben of verhinderd zijn, neemt u dan zo spoedig mogelijk contact op met de interviewer, Lukas Lange, via 06-17605799.

Met vriendelijke groet,
Dr. P.D.L.P.M. van der Valk, longarts

Appendix C. Informed Consent Sheet

Titel studie

Kwaliteit van leven bij COPD patiënten

Inleiding

U bent benaderd door Prof. dr. Job van der Palen om aan dit onderzoek deel te nemen. Uw toestemming of weigering moet u kunnen baseren op goede voorlichting. Daarom ontvangt u deze schriftelijke informatie. Na het lezen kunt u altijd nog vragen voorleggen aan de onderzoeker die aan het einde van deze informatie staat vermeld.

Doel en achtergrond van het onderzoek

Tijdens de behandeling van patiënten, is naast medische informatie (bijvoorbeeld bloedsuitslagen), het minstens net zo belangrijk om naar de kwaliteit van leven en het functioneren van patiënten te kijken. Hiervoor zijn in de loop van de jaren verschillende vragenlijsten ontwikkeld. Deze vragenlijsten zijn bedoeld voor patiënten met verschillende chronische aandoeningen. Het ontwikkelen van vragenlijsten specifiek voor COPD patiënten, is een tijdrovend en nauwkeurig proces. Van belang is dat de juiste vragen op de juiste manier geformuleerd worden, zodat deze voor iedereen duidelijk zijn en de juiste uitkomsten weergeven.

Om de zorg rondom COPD patiënten te verbeteren, willen we in dit onderzoek achterhalen hoe patiënten aankijken tegen bestaande vragenlijsten. Zijn de vragen duidelijk geformuleerd, goed te volgen? Is de vragenlijst als geheel prettig om in te vullen?

Natuurlijk kunnen wij dit niet zonder uw hulp en input. Dit onderzoek, welke bestaat uit het afnemen van een éénmalig interview, is een van de stappen in het proces tot het ontwikkelen van een nieuwe vragenlijst die specifiek is voor COPD patiënten, gericht op de kwaliteit van leven en functioneren in het alledaagse leven.

Wat houdt het onderzoek voor u in?

Als u wilt deelnemen aan het onderzoek zal er éénmalig een interview worden afgenomen. Dit zal ongeveer 60 tot 90 minuten in beslag nemen. Het interview vindt plaats in het ziekenhuis (Medisch Spectrum Twente). Voor het interview zullen wij medische gegevens

over de ernst van uw COPD bij uw arts opvragen. Deze gegevens zijn nodig om de resultaten beter te kunnen verwerken.

Tijdens het interview wordt u gevraagd om uw mening over een vragenlijst. Er bestaan hierbij geen juiste of onjuiste antwoorden, het gaat om uw mening en ervaring bij het invullen van de lijst.

Verder wordt van het interview wordt een geluidsopname gemaakt. Deze opname is van belang om het interview goed uit te kunnen werken. Daarnaast doet de onderzoeker tijdens het interview een aantal aantekeningen. Als het onderzoek is afgelopen wordt de opname uiteraard verwijderd.

Mogelijke voordelen

Ook wanneer u geen persoonlijk voordeel blijkt te hebben, is uw deelname zeker van belang. Dit onderzoek draagt bij aan de ontwikkeling van nieuwe vragenlijsten, waar mogelijk in de toekomst andere patiënten voordeel van kunnen hebben.

Vertrouwelijkheid

De gegevens die gedurende het onderzoek over u verzameld worden zullen vertrouwelijk behandeld worden volgens (inter)nationale regels en wetten, waaronder de Wet Bescherming Persoonsgegevens. De gegevens zullen zodanig gecodeerd worden dat ze niet tot u te herleiden zijn.

Indien u besluit deel te nemen aan dit onderzoek geeft u toestemming voor het volgende:

Medewerkers aan dit onderzoek en toezichhouders kunnen uw medische gegevens inzien. Zij zijn verplicht deze gegevens geheim te houden.

Indien u zou beslissen om uw deelname aan het onderzoek stop te zetten, mogen uw gegevens die verzameld werden vóór deze beslissing nog steeds verwerkt worden.

Vrijwillige deelname

U bent vrij deelname aan dit onderzoek toe te staan of te weigeren. Ook indien u nu toestemming geeft, kunt u te allen tijde zonder opgave van redenen weer intrekken. Wat u ook besluit, het zal geen enkele verandering teweeg brengen in de verzorging en begeleiding van u zelf.

Voor verder informatie

Als u vragen hebt over het onderzoek, kunt u die stellen aan Muirne Paap (onderzoeker Universiteit Twente), bereikbaar via telefoonnummer: 053-4892506, of via email: m.c.s.paap@utwente.nl.

Indien u geïnformeerd wilt worden over de uitkomst van dit onderzoek dan verzoeken we u om hieronder uw adres en/of emailadres te noteren:

'Kwaliteit van leven bij COPD patiënten'

Ik heb bovenstaande informatie gelezen en begrepen en verklaar mee te willen doen aan het onderzoek 'Kwaliteit van leven bij COPD patiënten'.

Naam:

Geboortedatum: . . - . . -

Handtekening:.....

Datum: . . - . . -

Appendix D. Interview guide

Ik wil u ten eerste hartelijk danken voor het feit dat u mee wilt werken aan dit onderzoek. Ik doe dit onderzoek in het kader van mijn Masteropdracht in de opleiding Psychologie van de Universiteit Twente. Met dit onderzoek hopen wij inzicht te verkrijgen in de ervaringen van COPD patiënten bij het invullen van de SGRQ-C. Het gaat om het testen van de vragenlijst, niet om het testen van uw responsen of prestatie. De vragenlijst is niet perfect en uw mening over de vragenlijst is belangrijk.

Wij gaan elke vraag individueel in twee delen benaderen. Deze twee delen worden verder opgedeeld in drie stappen. Pas in de derde stap wordt u gevraagd om u voorstellen, ideeën en meningen te uiten.

Stap 1 begint met de think-aloud methode. De think-aloud is een methode waar u hardop zegt wat u denkt als u het denkt tijdens het invullen van het item. U hoeft niet uw gedachten of antwoorden uit te leggen of te rechtvaardigen, u hoeft alleen hardop te zeggen wat in uw hoofd omgaat tijdens het beantwoorden van de vragen. Omdat dit waarschijnlijk de eerste keer is dat u deze taak zou uitvoeren, zullen we eerst met een voorbeeld oefenen.

Tijdens de tweede stap zal ik u vragen stellen die gaan over mijn observaties bij stap 1. Een voorbeeldvraag is: “U leest de vraag hardop en toen stopte U met het verwoorden van uw gedachten. Kunt u nog herinneren waarom u stopte?”.

Tijdens de derde stap zal ik u een aantal korte vragen stellen die gaan over uw mening over de vragenlijst of bepaalde vragen in de vragenlijst.

Het hele gesprek zal ongeveer 60 tot 75 minuten duren.

Als mijn vragen tijdens dit interview onduidelijk zijn, mag u dit aangeven. Voor een beter begrip van de vragenlijst is het belangrijk dat zo eerlijk en volledig mogelijk al mijn vragen beantwoord. Hebt u nog vragen voordat we beginnen met het interview?

Dan beginnen wij nu met het oefenen van de think aloud methode:

“Denk hard op tijdens het beantwoorden van de volgende vraag: Hoe vaak bent u boodschappen geweest afgelopen week.”

Appendix E. Table with possible recommendations for the SGRQ-C.

Table 5

Recommended changes for items of the SGRQ-C

Item	Subscale	Original Item/ Items	Recommended Item/ Items
1	Symptoms	Ik hoest: 1. De meeste dagen v. d. week 2. Meerdere dagen v. d. week 3. Alleen bij een luchtweginfectie 4. Helemaal niet.	Ik hoest: 1. Elke dag 2. De meeste dagen v. d. week 3. Meerdere dagen v. d. week 4. Alleen bij een luchtweginfectie 5. Helemaal niet.
2	Symptoms	Ik geef slijm op: 1. De meeste dagen v. d. week 2. Meerdere dagen v. d. week 3. Alleen bij een luchtweginfectie 4. Helemaal niet.	Ik geef slijm op: 1. Elke dag 2. De meeste dagen v. d. week 3. Meerdere dagen v. d. week 4. Alleen bij een luchtweginfectie 5. Helemaal niet.
3	Symptoms	Ik ben kortademig: 1. De meeste dagen v. d. week 2. Meerdere dagen v. d. week 3. Helemaal niet.	Ik ben kortademig: 1. Elke dag 2. De meeste dagen v. d. week 3. Meerdere dagen v. d. week 4. Helemaal niet.
4	Symptoms	Ik heb last van piepende ademhaling: 1. De meeste dagen v. d. week 2. Meerdere dagen v. d. week 3. Een paar dagen v. d. maand 4. Alleen bij een luchtweginfectie 5. Helemaal niet.	Ik heb last van piepende ademhaling: 1. Elke dag 2. De meeste dagen v. d. week 3. Meerdere dagen v. d. week 4. Een paar dagen v. d. maand 5. Alleen bij een luchtweginfectie 6. Helemaal niet.
5	Symptoms	Hoeveel zware of zeer onaangename aanvallen van ademhalingsproblemen had u gedurende het afgelopen jaar?	Hoeveel zware of zeer onaangename aanvallen van ademhalingsproblemen had u gedurende de afgelopen maand?

Item	Subscale	Original Item	Recommended item
25	Impact	Lichamelijke oefening is niet veilig voor mij. 1. Waar 2. Niet waar	Vraag verwijderen
29/32	Activity	Ik loop langzamer dan andere mensen of ik stop om uit te rusten. Als ik mij haast of snel loop, moet ik stoppen of langzamer lopen.	Verwijderen van een van de twee vragen.
33/34	Activity	Mijn ademhalingsproblemen maken het moeilijk om dingen te doen zoals een helling oplopen, dingen de trap opdragen, dansen, bowlen, golf spelen, of licht tuinwerk zoals wieden. Mijn ademhalingsproblemen maken het moeilijk om dingen te doen zoals zware dingen dragen, de tuin ompsitten of sneeuw ruimen, joggen of snel lopen (8 km per uur), tennissen of zwemmen.	Ik kan niet dingen de trap opdragen Ik kan niet dansen. Ik kan geen licht tuinwerk doen zoals wieden. Ik kan geen zware dingen dragen. Ik kan niet de tuin ompsitten of sneeuw ruimen. Ik kan niet zwemmen.
35	Impact	Ik kan niet aan sport of spel doen	Ik kan niet aan sport doen. Ik kan niet aan bordspelen doen.
39	Impact	Ik kan niet ver van mijn bed of stoel komen	Vraag verwijderen