How could e-health be used to enhance the self-management of COPD patients?

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Enschede
Abstract

Objective: The objective of this research is to evaluate how COPD patients could be supported to develop onto a higher level of self-management by means of e-health technology.

Background: Due to the high prevalence of chronic obstructive pulmonary disease (COPD) and the impairment of quality of life of COPD patients, the efficiency of healthcare and the patients’ autonomy and self-management skills gain more and more importance. Self-management interventions could be particularly useful for this target group.

Method: This research is a secondary analysis of primary data. A directive content analysis has been executed. The data used, consisted of semi-structured interviews with ten Dutch COPD patients. The coding scheme has been established based on Ajzen’s Theory of Planned Behavior (1991) and Schermer’s Three Levels of Self-management (2009). The current levels of self-management of COPD patients and their attitudes, perceived subjective norm and perceived behavior control regarding self-management have been analyzed.

Results: Most participants perform behavior of the first and second level of self-management. Nine out of ten participants hold negative attitudes regarding self-management. The attitude that is mentioned the most, is that the patients do not want a change in their current health care process. Regarding perceived behavior control, it can be said that one half of the participants report not having problems with using the inhalator correctly. The other half reports to have problems due to shortness of breath, cough, hastiness or forgetting the right instructions.

Conclusion: The results of this analysis indicate that COPD patients perform self-management on a low level and that this might be influenced by the patients’ negative attitudes regarding self-management. Therefore, to be able to support COPD patients to develop onto a higher level of self-management, it seems to be important to address their negative attitudes in future e-health self-management interventions.
E-HEALTH SELF-MANAGEMENT INTERVENTION FOR COPD PATIENTS

Samenvatting

Doel: Het doel van dit onderzoek is te evalueren hoe COPD patiënten door e-health technologie geholpen kunnen worden om zelfmanagement gedrag op een hoger niveau te vertonen.

Achtergrond: Op grond van de hoge prevalentie van de Chronisch obstructieve longziekte (COPD) en de beperking van de levenskwaliteit van COPD patiënten wordt het steeds belangrijker om de efficiëntie van het gezondheidssysteem en de autonomie van de patiënt te verhogen. Zelfmanagement interventies zouden vooral voor deze doelgroep van groot belang kunnen zijn.


Resultaten: De meerderheid van de respondenten vertonen zelfmanagement gedrag op het eerste en tweede niveau van zelfmanagement. Negen van tien respondenten hebben een negatieve houding tegenover zelfmanagement. De houding, die het meest word genoemd, is dat de respondenten niet bereid zijn voor een verandering in hun gezondheidszorg. Daarnaast, geeft een half van de respondenten aan hun inhalator niet op de juiste manier te gebruiken. Redenen daarvoor zijn: kortademigheid, hoest, haast of het vergeten van instructies.

Conclusie: Respondenten vertonen zelfmanagement gedrag op een laag niveau. De resultaten van dit onderzoek suggereren dat dit misschien in een verband zou kunnen staan met de negatieve houdingen van de respondenten. Om patiënten te kunnen helpen zich tot een hoger niveau van zelfmanagement te ontwikkelen, zou het belangrijk kunnen zijn de negatieve houdingen in een e-health zelfmanagement interventie tegen te gaan.
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1. Introduction

1.1 COPD

COPD is the abbreviation for Chronic Obstructive Pulmonary Disease which is characterized by a chronic narrowing of the bronchial tubes. COPD patients suffer from several symptoms, including severe cough, shortness of breath and increased phlegm (GOLD, 2016). The quality of life for COPD patients is impaired not only in physical but also in emotional and social areas of life (Tabak & Tijhuis, 2002).

1.1.1 Causes

The common cause of COPD is cigarette smoking (GOLD, 2016). However, not all smokers develop the disease, and in a minor number of non-smoking people the illness can also be diagnosed. This is due to the fact that smoking is only one of a number of risk factors for the development of COPD. As well as smoking, the development of COPD may also be influenced by a gene-environment interaction. This term includes genetic predisposition and environmental conditions, such as gender or socioeconomic status, which all play a role in the development of the disease. Gender could, for example, influence the decision to start or not start smoking. Another cause can be the inhalation of pollutants, such as organic or inorganic dusts and chemical fumes (GOLD, 2016).

1.1.2 Prevalence, Incidence and Mortality

In 2011, 189,700 men and 172,100 women in the Netherlands suffered from COPD. 3,466 men and 2,887 women from this group died of COPD in the same year. The illness is mainly found in people aged 55 and older and the prevalence increases with age (RIVM, 2014).

According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2016) more smokers and ex-smokers than nonsmokers are affected by COPD. Furthermore, the risk of falling ill with COPD seems to be higher for men than for women. One possible
explanation could be that more men than women smoke. Also, people older than 40 years of age are more likely to develop the illness. The reason for this is still unclear. However, it could be related to the accumulated exposures to risk factors over time (GOLD, 2016).

The research of Afonso, Verhamme, Sturkenboom and Brusselle (2011) shows that from the 1,713 non-COPD respondents, who were older than 40 years of age, the risk for developing COPD in the next 40 years was 12.7% for men and 8.3% for women. From the patients who were diagnosed with very severe COPD, 26% died within one year. From the respondents without COPD this percentage was only 2.8%.

1.1.3 Consequences

The consequences of COPD can be divided into the patient’s personal consequences from having COPD and the societal consequences of the disease. Concerning the patient's personal consequences of COPD, it can be said that the illness affects different aspects of life. These include family life, employment, sexuality, emotional functioning and quality of life. (Hansen, 1982; Zamzam, Azab, El Wahsh, Ragab & Allam, 2012). Furthermore, patients diagnosed with moderate or severe COPD often suffer from depression (Light, Merrill, Despars, Gordon, & Mutalipassi, 1985). It seems that of the 45 examined COPD patients, 42% were suffering from depression (Light et al., 1985). Factors that seem to have an influence on quality of life in COPD patients are: self-esteem, depression, social support and age (Anderson, 1995).

With respect to the societal consequences, the economic burden associated with COPD is important to consider. The ten-year population based study by Khakban et al. (2015) examines the direct costs of COPD in the Canadian population. Their sample consists of 153,570 COPD patients who had at least one COPD related hospitalization and 246,801 non-COPD patients. All patients were older than 35 years of age. The research shows that the
health care costs for COPD patients ($8,600/y) in comparison to non-COPD patients ($3,148/y) were 2.73 times higher. Furthermore costs increased over time by $5,452/y per patient. That means an increase of 38% between 2001 and 2010. The largest components of total care costs of COPD patients were hospital admissions, followed by costs of medications (Khakban et al., 2015). In 2007, the health care costs for COPD in the Netherlands were around 415 million euro. That means that per year, approximately 1.350 euro were spent per COPD patient (Suijkerbuijk et al., 2013).

### 1.1.4 Diagnosis and Treatment

For adequate treatment of COPD, the degree of severity of COPD has to be established. Therefore physicians usually use the GOLD stage model which divides COPD in four stages. The classification is made based on the air flow limitation severity. Stages one to four are described as: mild, moderate, severe and very severe (GOLD, 2016).

According to the COPD diagnosis, management and prevention guidelines published by GOLD (2016), the treatment of COPD can be divided up into medical and non-medical treatment. Medical treatment can include pharmacological or non-pharmacological therapy. The pharmacological therapy usually involves inhalation medication. Medications usually used for the treatment of COPD are Bronchodilators, Corticosteroids and Phosphodiesterase-4 Inhibitors. While bronchodilators improve the widening of the respiratory tract, the latter two reduce inflammation. Examples of non-pharmacological, medical treatments are surgical treatments, such as Lung Volume Reduction Surgery (LVRS) or Lung Transplantation. Another example would be oxygen therapy, which involves the long-term supply of oxygen to the patient.

An important part of the treatment of COPD patients is to quit smoking. Smoking cessation can be stimulated by either medical or non-medical therapy. The medical way of
supporting smoking cessation would be by pharmacotherapy or nicotine replacement. A non-medical treatment could be in the form of counseling. Other non-medical treatments include exercise training, education and nutritional support (GOLD, 2016). One of the functions of these non-medical treatments is to enhance the self-management of COPD patients (Monninkhof, van der Valk, van der Palen, van Herwaarden, Partridge and Zielhuis, 2003). In the following section self-management will be addressed. Against the background of an aging society, where more health care is needed and health care expenditures are increasing, self-management gains more and more importance (Bodenheimer, Lorig, Holman & Grumbach, 2002). Self-management can not only be valued for its contribution to the health care efficiency, but also for its enhancement of the independence and autonomy of a patient (Schermer, 2009).

1.2 Self-management

Self-management is defined by Clark et al. (1991) as: “day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status. At-home management tasks and strategies are undertaken with the collaboration and guidance of the individual’s physician and other health care providers” (p.5). Self-management can be seen as an attempt to give patients control in managing their disease and make them capable of working together with their health care professional and the health care system. Self-management programs address topics such as medication use, emotion management and disease related knowledge and skills, thus preparing the patient to actively make their own health related decisions (Lorig, Sobel, Ritter, Laurent & Hobbs, 2000). The patient is encouraged to actively find a suitable balance between medical requirements and his own values in life (Schermer, 2009).
1.2.1 Self-management and COPD

Positive outcomes were found regarding the effect of self-management interventions on health of chronic disease patients. This can be seen in the research by Lorig et al. (1999) which measured the effectiveness of a self-management program on patients who were diagnosed with a chronic disease. In this research, subjects who were part of the self-management program and a control group were compared in their health behavior, status and service utilization. The outcomes show that subjects who took part in the program improved in multiple aspects, such as the degree of exercising, symptom management, self-reported health, alertness and social or employment functioning. As well as this, the amount of hospital stays was reduced significantly (Lorig, 1999).

Various positive effects of self-management interventions, particularly directed at COPD patients, were also found. Monninkhof et al. (2003) analyzed 12 research articles aimed at measuring the effect of self-management education on COPD patients. Based on this systematic review, it can be said that self-management education seems to have a positive influence on the use of medication and leads to a reduction of the need for rescue medication. The review of Adams, Smith, Allan, Anzueto, Pugh and Cornell (2007) shows a reduction in hospital admission in COPD patients who took part in a self-management intervention. This also seems to have a direct impact on healthcare costs. After self-management training, health care costs declined between 34% up to 70% in the intervention group. This decline can be mainly explained through reduced hospitalization (Adams et al., 2007). Furthermore, COPD patients reported an increased feeling of safety after self-management education (Gallefoss & Bakke, 2002).

According to Chen, Chen, Lee, Cho and Weng (2008), the five most important self-management behaviors of COPD patients are: symptom management, activity and exercise implementation, environmental control as temperature and humidity control, emotional
adaption and maintaining a healthy lifestyle. Effing et al. (2012) recommend five components that should be included in self-management programs for COPD patients. These are: smoking cessation advice and support, action plans for the treatment of exacerbation, exercise programs, nutritional advice and training of breathless management strategies (Effing et al., 2012). Nowadays, these self-management programs are often implemented in the form of electronic health management (e-health) interventions (Oh, Rizo, Enkin & Jadad, 2005). Examples of e-health self-management interventions include computer programs to use at home, videotaped counselling from a professional, computer-generated advice mailed to the patients, online video group sessions and videotaped exercise training (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002).

1.3 E-health

There is no universally accepted definition of e-health yet, but it usually implies the use of information and communication technologies to improve health and the health care system (Oh, Rizo, Enkin & Jadad, 2005). A frequently used definition of e-health was developed by Eysenbach (2001): “e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” (p. 1). By using e-health interventions, patients are able to improve their self-management behavior and they are supported by self-management education and treatment plans. Furthermore, they are fostered to develop skills to measure and interpret their own physical conditions (Hardinge et al., 2015). E-health devices provide the interaction between patients and health professionals, the transmission of medical data and to facilitate the communication between patients. E-health
technologies can be implemented in many different ways, for example, in the form of telemedicine services, internet networks or health data recording facilities (Arning, Ziefle, & Arning, 2008).

### 1.3.1 Effects of e-health

Based on research by Akematsu and Tsuji (2009), it can be extrapolated that the usage of e-health technologies has a positive effect on the reduction of healthcare expenditures. The research compared the healthcare expenditures of 199 users of e-health technology, which supported the health status of elderly people at home, with 209 non-users of technology. A telecommunications network sent the health related data of the patients, such as blood pressure, blood oxygen and ECG, to a medical institution. The results show that e-health technology users had approximately 21% less annual healthcare expenditures than non-e-health technology users. Furthermore, e-health technology users who had already used e-health technology had greater reduced costs than e-health technology users who started using it recently (Akematsu & Tsuji, 2009).

Another effect of e-health can be seen in the literature study of Linn, Vervloet, van Dijk, Smit & Van Weert (2011) which shows that internet interventions improve medication adherence. From thirteen of the included studies in the research, five studies showed a significant effect on medication adherence, six studies reported a moderate effect and only 2 showed no effect at all (Linn et al., 2011).

Furthermore, COPD patients using e-health technology had four times less the number of hospital stays per year than patients not using e-health technology (Hillestad et al., 2005). Next to that, COPD patients using e-health technology annually had fewer days where they were unable to work than patients not using e-health technology. (Hillestad et al., 2005).
1.3.2 E-health self-management interventions for COPD patients

There exist various e-health interventions aimed at enhancing self-management of COPD patients. To provide insight in the different forms of e-health interventions, four examples will be mentioned here. The first example is an online website where COPD patients can choose between different behavior modules. The behavior modules include the assessment of the patients’ beliefs regarding a particular behavior and experienced barriers, the delivery of feedback and the development of action plans (Voncken-Brewster, Moser, van der Weijden, Nagykaldi, de Vries, Tange, 2013). The second example is an intervention implemented in the form of an internet-linked tablet computer. This intervention provides information through videos and texts. Additionally, it monitors the patient’s health by measuring heart rate and oxygen saturation, and it includes symptom diaries and self-management plans (Farmer, Toms, Hardinge, Williams, Rutter & Tarassenko, 2014). The third example is an intervention which makes use of different technological devices: the patient’s TV, computer and a remote control. This intervention provides self-management education in groups or individually (Burkow, 2013). The fourth example is an app for mobile phones. It has been developed with the aim of increasing the daily physical activity of COPD patients (Vorrink, Kort, Troosters & Lammers, 2016).

Regarding the effect of e-health self-management interventions for COPD patients, it can be said that the physical activity app, mentioned above, was found by patients to be stimulating (Vorrink et al., 2016). Furthermore, patients appreciated the social aspect of online group education (Burkow, 2013) and evaluated e-health self-management education positively (Hardinge et al., 2015).

Verwey, van der Weegen, Spreeuwenberg, Tange, van der Weijden and de Witte (2014) evaluated an e-health self-management program aimed at stimulating the physical activity in COPD patients. The program included an accelerometer, a smartphone app and a
web application. Ten COPD patients took part in the intervention for three months. It can be concluded that, by taking part in the program, the patient’s awareness of his or her behavior increased. Furthermore, a positive effect on the patient’s feeling of autonomy was reported. The program seemed to stimulate the patients to become more active and, after completing the intervention, patients rated their quality of life higher (Verwey et al., 2014). All in all, it can be said that there are various e-health self-management interventions for COPD patients and that positive effects have been reported from many of them. However, e-health is a relatively new field of research and against the background of an aging society, where health care efficiency becomes more and more important, more research in the field of self-management and e-health is necessary (Bodenheimer, 2002).

2. Theoretical framework

According to van Gemert-Pijnen et al. (2011) e-health technology can best be developed by following the CeHRes Roadmap. The CeHRes Roadmap shows a holistic approach to the development of e-health technology and can be used as practical guideline to plan, coordinate and execute the development of e-health technologies (van Gemert-Pijnen et al., 2011). A schematic representation of the CeHRes Roadmap can be found in Figure 1 (van Gemert-Pijnen et al., 2011, p.9)
The first step of the development of an e-health technology should be, according to the CeHRes Roadmap, the ‘Contextual Inquiry’. During this step, information about the potential users and their environment is accumulated. The second step ‘Value Specification’ involves the specification of user requirements by elaborating their economic, medical, social or behavioral values. During the third step ‘Design’, the user requirements are then transposed into technical requirements and realized in a prototype. The fourth step ‘Operationalization’ implies the actual application of the device in public. During the fifth and final step, the ‘Summative Evaluation’ is carried out. Through this, the positive and negative outcomes of the usage of the e-health device are measured (van Gemert-Pijnen, 2011).

With the help of the CeHRes Roadmap, a meaningful, manageable and sustainable e-health technology intervention can be developed (van Gemert-Pijnen, 2011). This research focuses on the first and second step of the CeHRes Roadmap, the ‘Contextual Inquiry’ and ‘Value Specification’. Based on that, recommendations for the third step, the ‘Design’, can be given.

To gather information for the step ‘Contextual Inquiry’, the current level of self-management of COPD patients is examined. This is important, because it decreases the risk of...
developing an e-health device which overextends the patients’ self-management capabilities and would expose the patient to a safety risk. Secondly, it increases the patients’ possibility of achieving their full self-management potential by supporting self-management originating from already acquired behavior. To be able to assess the patient’s self-management level the three levels of self-management developed by Schermer (2009) are used.

To gather information for the step ‘Value Specification’, the underlying factors which determine if patients do or do not perform self-management behavior are examined. Therefore, the ‘Theory of Planned Behavior’ (Ajzen, 1991) is used, because it explains which factors are involved in the decision making process concerning the evaluation of whether a behavior of interest will be performed or not. This knowledge can be used for the step ‘Design’. By knowing the underlying factors that determine a patient’s behavior, an e-health intervention, which influences these factors, could be developed. From this, patients might be encouraged to have and develop a higher level of self-management. This in turn, could, firstly, have a positive impact on the COPD patient’s life by enhancing his autonomy, and secondly, reduce the economic burden of COPD by decreasing hospital admissions and increasing health care efficiency.

2.1 Three levels of self-management
In this research, the three levels of self-management developed by Schermer (2009) will be used. The first two levels are classified as ‘compliant self-management’, while the third level is called ‘concordant self-management’. A patient who can be attributed to the first level of self-management is able to apply learnt methods, but does not make his own decisions regarding his health. At this level there is no autonomy. A patient in the second level of self-management is able to carry out interpretative and decisional tasks, but he is not able to develop his own opinions on the health care process. A patient in the third level of self-management is able to make his own decisions in regard to the disease management. The
relationship between a patient in level three and the professional is characterized through cooperation and agreement. According to Schermer (2009) the third level of self-management is ideal, because it enhances both the patient’s independence and well-being. To achieve this third level of self-management both patient and professional have to actively participate in the health care process (Schermer, 2009).

### Table 1

*The Three Levels of Self-management developed by Schermer (2009)*

<table>
<thead>
<tr>
<th>Level of self-management</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>First level</td>
<td>The respondent is able to apply acquired practical tasks associated with his health care, but does not make his own decisions regarding his health management</td>
</tr>
<tr>
<td>Second level</td>
<td>The respondent is able to carry out interpretative and decisional tasks associated with his health care, but he is not able to develop his own opinions or viewpoints on the health care process.</td>
</tr>
<tr>
<td>Third level</td>
<td>The respondent is able to make his own decisions with regard to the health care process.</td>
</tr>
</tbody>
</table>

#### 2.2 Theory of Planned Behavior

The ‘Theory of Planned Behavior’ states that if someone performs a behavior of interest, is determined by three components: one’s attitude toward the behavior, the perceived subjective norm and one’s perceived behavioral control. Attitude refers to the evaluation someone has about the behavior concerning its outcomes. Subjective norm refers to the person’s belief about how other people would evaluate the behavior. Perceived behavior control is a persons’ perception of his or her capabilities regarding the performance of the behavior. (Ajzen, 1991). A schematic representation of the theory of planned behavior can be found in Figure 2.
2.3 Research questions

Main research question

1. How could e-health be used to enhance the self-management of COPD patients?

Sub-questions

1.1 What are the current levels of self-management of COPD patients?

1.2 What attitudes do COPD patients have regarding self-management behavior?

1.3 How do COPD patients perceive the subjective norm regarding self-management?

1.4 How do COPD patients perceive their behavior control regarding self-management behavior?

1.5 How could COPD patients be supported to develop onto a higher level of self-management?
3. Methods

This research is a secondary analysis of primary data. The data consists of semi-structured interviews with COPD patients. In this research, a directed content analysis will be executed.

3.1 Participants

Six male and six female Dutch patients with a chronic lung disease participated in this research. Two female patients had to be excluded from further analysis, because they were not diagnosed with COPD, but with another lung disease. In total, the interviews with 10 COPD patients are included in this research.

The mean age of the participants was 64 years. The youngest participant was 41 and the oldest 80 years old. Table 2 shows the demographic characteristics of the participants. Participants had to be 18 years or older and use an inhaler for a chronic lung disease. Participants were recruited by convenience and snowball sampling. All participants signed an informed consent. After participation, the participants were rewarded with a gift voucher.
## Table 2

**Demographics per participant**

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Sex</th>
<th>Age</th>
<th>Working status</th>
<th>Level of education</th>
<th>Number of years since diagnosis</th>
<th>Family situation</th>
<th>Technology use</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>60</td>
<td>Unemployed</td>
<td>Low</td>
<td>7</td>
<td>Married, 2 children</td>
<td>Computer with internet access &amp; smartphone</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>66</td>
<td>Retired</td>
<td>Low</td>
<td>5</td>
<td>Single widower, 2 children</td>
<td>Computer with internet access &amp; smartphone</td>
</tr>
<tr>
<td>3</td>
<td>Male</td>
<td>73</td>
<td>Retired</td>
<td>Low</td>
<td>27</td>
<td>Married, 3 children</td>
<td>Computer with internet access</td>
</tr>
<tr>
<td>4</td>
<td>Male</td>
<td>66</td>
<td>Retired</td>
<td>Middle</td>
<td>6</td>
<td>Married, 3 children</td>
<td>Computer with internet access</td>
</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>80</td>
<td>Retired</td>
<td>High</td>
<td>20</td>
<td>Widower, 3 children</td>
<td>No computer, no smartphone</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>50</td>
<td>Working</td>
<td>Middle</td>
<td>-</td>
<td>Married, 2 children</td>
<td>Computer with internet access &amp; smartphone</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>65</td>
<td>Retired</td>
<td>Low</td>
<td>31</td>
<td>Married, 3 children</td>
<td>Computer with internet access &amp; smartphone</td>
</tr>
<tr>
<td>8</td>
<td>Female</td>
<td>66</td>
<td>-</td>
<td>Middle</td>
<td>12-15</td>
<td>Widow, 3 children</td>
<td>Computer with internet access &amp; smartphone</td>
</tr>
<tr>
<td>9</td>
<td>Male</td>
<td>76</td>
<td>Retired</td>
<td>Middle</td>
<td>20</td>
<td>Married</td>
<td>Computer with internet access &amp; smartphone</td>
</tr>
<tr>
<td>10</td>
<td>Female</td>
<td>41</td>
<td>Working</td>
<td>Middle</td>
<td>-</td>
<td>In a relationship, 1 child</td>
<td>Smartphone (no information about computer use)</td>
</tr>
</tbody>
</table>

Note. ¹high: hbo bachelor, hbo master, wo bachelor, wo master, doctor; middle: havo, vwo, mbo2, 3 and 4, low: vmbo, mbo1, first and second year of havo and vwo (CBS, 2006)
3.2 Materials
The semi-structured interviews consisted of 23 questions aimed at assessing the participants’ problems and needs regarding health related issues. The interviews were divided up into three topics: ‘demographic’, ‘healthcare specifics’ and ‘technological specifics’. The main focus of the interview was the respondent’s inhalator use. The interviews were conducted in Dutch. An example of a question of the topic ‘healthcare specifics’ is: ‘How would you like to be supported in using your inhaler properly?’.

For the data analysis of the current research the program Atlas.ti has been used.

3.3 Procedure
This research is a qualitative research and aligns with the naturalistic paradigm. The naturalistic paradigm states that multiple realities exist, depending on the interpretation of each individual. Therefore respondents have to be studied individually and the data has to be analyzed qualitatively. This is the only way that an accurate insight in the reality of the respondent can be gained. The aim of the research is to understand the subjective experiences of the respondents (Keele, 2012).

For the objective of this research, a directed content analysis is most suitable, because an already existing theory will be used to analyze qualitative data. Content analysis is a popular research tool in health studies to analyze text data with the focus on the contextual meaning of the text. Directed content analysis is mostly used when there already exists research in the field of interest, which makes it impossible to work from a complete naïve perspective (Hsieh & Shannon, 2005).

Firstly, before beginning with the analysis, all key concepts of the used theories were identified as initial coding categories. These were: first-, second-, and third level of self-management, positive and negative attitude, positive and negative subjective norm and high
and low perceived behavior control. Secondly, based on the theories a definition was attributed to each category. The initial coding scheme can be found in Table 3. At the beginning of the analysis, all interviews were read and all information that initially appeared to be associated with self-management was highlighted. Then, the codes from the initial coding scheme (see Table 3) were allocated to the highlighted parts. Passages that could not be coded with the initial coding scheme were attributed with a new code. Afterwards, all interviews were reviewed and, where appropriate, coded again. (Hsieh & Shannon, 2005). Finally, a second coder assigned codes to 10% of the text passages, and Cohen’s Kappa was calculated to 0.86, which can be interpreted as very good interrater reliability (Landis & Koch, 1977).

Ethical approval for the interview study was obtained by the ethics committee of the faculty of Behavioral, Management and Social Sciences of the University of Twente.

3.4 Data analysis

For every participant, all behavior coded either as self-management level one, level two or level three, was individually summarized and listed in key points. Afterwards, the enumerated behaviors of the participants were compared with each other in regard to their quality and quantity. Based on that, the self-management of each participant has been evaluated. Furthermore, the summarized content of every quote belonging to the codes ‘positive or negative attitude’, ‘positive or negative perceived subjective norm’ or ‘high or low perceived behavior control’ was listed in key points for each participant. Then, all different positive and negative attitudes were extracted and their frequency of occurrence was determined. The same procedure has been executed for perceived subjective norm and perceived behavior control.
### Table 3

*The Initial Coding Scheme*

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
</tr>
</thead>
</table>
| **First level of self-management** | - The respondent is able to apply acquired practical tasks associated with his health care  
- The respondent does not make his own decisions regarding his health management  
- His own opinions or wishes are not integrated in the health care process  
- The patient’s autonomy is not enhanced |
| **Second level of self-management** | - The respondent is able to carry out interpretative and decisional tasks associated with his or her health care  
- The respondent can interpret measurement data and if necessary can adjust medication or lifestyle aspects  
- The respondent is more independent of professionals than during level one  
- The respondent is not able to develop his own opinions or viewpoints on the health care process |
| **Third level of self-management** | - The respondent has relevant knowledge, understanding and practical abilities to develop his own manner of living with COPD  
- The respondent is able to make his own decisions with regard to the health care process  
- He is the leader of his life and collaborates with a professional only when necessary |
| **Positive attitude** | - The respondent expects positive outcomes from the self-management behavior |
| **Negative attitude** | - The respondent expects negative outcomes from the self-management behavior |
| **Positive subjective norm** | - The respondent believes that other people would evaluate the self-management behavior positively |
| **Negative subjective norm** | - The respondent believes that other people would evaluate the self-management behavior negatively |
| **High behavior control** | - The respondent believes that he or she is capable of performing the self-management behavior successfully |
| **Low behavior control** | - The respondent believes that he or she might not be capable of performing the self-management behavior successfully |
4. Results

The outcomes of the analysis show that no clear distinction can be made between the different levels of self-management. Five of the ten participants seem to perform self-management behavior belonging to different levels of self-management. In the following paragraphs, the common self-management behaviors for each self-management level will be given. An overview of these outcomes can be found in Table 4.

4.1 Classification of behavior attributed to the first level of self-management

Behavior attributed to the first level of self-management involves the performance of practical tasks demanded by the doctor. All ten participants report that they use an inhalator prescribed by a doctor. However, behavior of the first level does not involve the creation of own ideas to improve the living condition nor the development of own viewpoints on the health care process (Schermer, 2009). In this sample, three participants are unable to think of possibilities to improve their own health care.

*Quote 1* “*In what way do you think you could be supported to execute the instructions for using the inhalator every time in the right way?* That is a good one... I cannot give an answer on that right now. No, I do not know this.” (Participant 1)

Another behavior that is characteristic for the first level of self-management is that patients do not search actively for information. This applies to eight participants. They receive the information passively from their doctor (n=3), doctor assistant (n=2) nurse practitioner (n=7), pharmacist (n=1) or the package leaflet (n=2).

*Quote 2* “Firstly, we always get a detailed information letter from the pharmacy, on which is written what I take and how often I have to take it...but there is no instruction on how I have to take it. But I am not such a computer-savvy person, for example you could search this via the computer. But I do this hardly ever.” (Participant 3)
In total five participants mention how they would react in an emergency situation, such as extreme shortness of breath. The behavior of two of the participants can be attributed to the first level of self-management. They would not know what action to take and they would call the doctor or a hospital. However, for one of the participants this could be related to his high stage of COPD and not to his level of self-management, because he states that even the doctor could not help him in such a situation.

Quote 4 “[Imagine you get an attack and suddenly feel extreme short of breath. What would help you to inhale, as fast as possible and also using the right method, so that you would feel less short of breath soon?] To try to stay relaxed, so that, firstly, I won’t panic. This also happened to me in the past, and also once that I called the doctor afterwards. Typically, these kinds of things happen at the weekend, when the regular doctor isn’t there. “(Participant 9)

4.2 Classification of behavior attributed to the second level of self-management

Second level self-management behavior implies the use of various different sources to actively search for COPD related information. The participants used: COPD related websites (n=2), forums and personal contact with other COPD patients (n=3), COPD related courses (n=3) and an online dictionary for medical terms (n=1).

Quote 5 “Next to that, I look on the website for information and there is also a forum, which I use sometimes.” (Participant 6)

Another behavior that can be classified as second level self-management is to carry out interpretative and decisional tasks associated with the health care (Schermer, 2009). Three of
the five participants, who mention situations of extreme shortness of breath, state that they have an extra inhalator they use in these kinds of situations. They are able to recognize an emergency situation and decide for themselves if they have to use the extra inhalator.

*Quote 6 “And finally, I have an extra inhalator. I use it when I am really short of breath, thus really in emergencies.” (Participant 2)*

Two participants, performing second level self-management behavior, are also able to make decisional task regarding life style aspects that improve their emotional wellbeing.

*Quote 7: “You are less and less able to do things, so you keep searching in different corners to find something you are able to do.” (Participant 7)*

*Quote 8: “You have to look out for yourself, so that you don’t get upset through the fact that some things sometimes just don’t succeed.” (Participant 9)*

Three participants mention, that they are able to adjust their medication depending on the severity of their symptoms. They use different devices to help them manage their disease and support them in their decisions regarding their health. Two of the patients use an online COPD coach, to whom they can ask questions in an online chat. Both patients state that they use the COPD coach once a week and that at the end of the week, they have to fill in a questionnaire regarding their current health status. One patient uses the alarm of her mobile phone to remind her of her medication every evening. Another patient uses a ‘traffic light system’, where based on her current symptoms she gets assigned to the green, yellow or red stage. Depending on the stage, she is allowed to adjust her medication.

*Quote 9: “I was allowed to self-manage it [her medication] and then, you had to increase your inhalator use and you were not allowed to forget that.” (Participant 10)*
4.3 Classification of behavior attributed to the third level of self-management

The difference between the self-management behavior of the second and third level of self-management is that the self-management behavior of the third level is more independent of a professional than in the second level. In the third level of self-management patients make decisions that are not in accordance with their professional, but that truly rely on their own opinions and viewpoints (Schermer, 2009). For example, one participant describes that if he feels worse, he raises his medication even if that is not in agreement with his professional.

Quote 10: “If I am really short of breath, than I also take one [medication] during the day, because I am the boss and the doctor does not feel this, but I do.” (Participant 9)

Patients performing self-management behavior of the third level have developed their own manner of living with COPD. They not only use devices to support their self-management, they actively adjust devices to be best suitable for their situation. For example, one patient describes that she uses an app, made for a drinking game, to meter her medication consumption.

Quote 11: “On my phone I have an app and I use it to count [the medication use], so that I can remember the amount. [Okay, and is this a particular app for the medication use?] [...] No, this one is actually, to tell how many drinks everyone had in a bar. But it was the only app I could find to count something.” (Participant 6)
### Table 4

**Classification of behavior attributed to the different levels of self-management**

<table>
<thead>
<tr>
<th>Level of self-management</th>
<th>Self-management behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>First level</strong></td>
<td><strong>Performance of practical tasks</strong></td>
</tr>
<tr>
<td></td>
<td>- inhalator use (n=10)</td>
</tr>
<tr>
<td></td>
<td><strong>No development of own viewpoints</strong></td>
</tr>
<tr>
<td></td>
<td>- are unable to think of possibilities to improve own healthcare (n=3)</td>
</tr>
<tr>
<td></td>
<td><strong>No active search for information</strong></td>
</tr>
<tr>
<td></td>
<td>- doctor (n=3)</td>
</tr>
<tr>
<td></td>
<td>- doctor assistant (n=2)</td>
</tr>
<tr>
<td></td>
<td>- nurse practitioner (n=7)</td>
</tr>
<tr>
<td></td>
<td>- pharmacist (n=1)</td>
</tr>
<tr>
<td></td>
<td>- the package leaflet (n=2)</td>
</tr>
<tr>
<td></td>
<td><strong>No decision-making</strong></td>
</tr>
<tr>
<td></td>
<td>- do not know how to handle an emergency situation of extreme shortness of breath (n=2)</td>
</tr>
<tr>
<td><strong>Second level</strong></td>
<td><strong>Active search for information</strong></td>
</tr>
<tr>
<td></td>
<td>- COPD related websites (n=2)</td>
</tr>
<tr>
<td></td>
<td>- forums and personal contact with other COPD patients (n=3)</td>
</tr>
<tr>
<td></td>
<td>- COPD related courses (n=3)</td>
</tr>
<tr>
<td></td>
<td>- online dictionary for medical terms (n=1)</td>
</tr>
<tr>
<td></td>
<td><strong>Decision making</strong></td>
</tr>
<tr>
<td></td>
<td>- are able to recognize emergency situations and decide when to use extra inhalator (n=3)</td>
</tr>
<tr>
<td></td>
<td>- make decisions to improve emotional wellbeing (n=2)</td>
</tr>
<tr>
<td></td>
<td>- adjust medication (n=3)</td>
</tr>
<tr>
<td></td>
<td><strong>Use different devices to support them in their decisions</strong></td>
</tr>
<tr>
<td></td>
<td>- COPD coach (n=2)</td>
</tr>
<tr>
<td></td>
<td>- alarm from mobile phone (n=1)</td>
</tr>
<tr>
<td></td>
<td>- traffic light system (n=1)</td>
</tr>
<tr>
<td><strong>Third level</strong></td>
<td><strong>Development of own manner of living with COPD</strong></td>
</tr>
<tr>
<td></td>
<td>- adjust medication without agreement with professional (n=1)</td>
</tr>
<tr>
<td></td>
<td>- use of an app for the health care process originally made for a different purpose (n=1)</td>
</tr>
</tbody>
</table>
4.4 Allocation of the participants to the different levels of self-management

Two patients exhibit behavior belonging only to the first level of self-management. Three patients show self-management behaviors of both the first and the second levels of self-management. These patients are classified in Figure 3 as belonging to level one and a half. Three patients exhibit only second level self-management behavior. Additionally, two patients show not only second level behavior, but also some third level self-management behavior. They are classified in Figure 3 as belonging to level two and a half. An overview of the results can be found in Figure 3.

![Graph showing level of self-management for every COPD patient.](image)

*Figure 3. Level of self-management for every COPD patient*

4.5 The participants’ attitudes regarding self-management behavior

In this sample, five of the COPD patients have negative as well as positive attitudes regarding self-management behavior. Only one participant mentions no negative attitudes at all, while four participants mention no positive attitudes at all. First of all, the negative attitudes will be considered.
4.5.1 Negative Attitudes

The opinion that most (n=7) of the participants mention is that they do not want the health care process, as it is now, to change. Three participants explain that they have already had COPD for a long time and that they are satisfied with their current health care.

*Quote 12:* “No, I don’t see the benefits of this, because it went well like this all those years.” *(Participant 1)*

One participant states that he cannot imagine any benefits of more self-management behavior at all. The other three participants give no clear explanation for their attitude.

*Quote 13:* “I really don’t want to do this [using the Internet to get information about the inhalator use]. There are also forums for lung patients on facebook. No, sorry, but that isn’t something for me. I don’t want all of this nagging and groaning.” *(Participant 7)*

Furthermore, participants perceive self-management in comparison to traditional health care as more time consuming (n=3), expensive (n=1) or laborious (n=3).

*Quote 14:* “[…] I think it [the proposed self-management behavior] would cost once again extra time, because you get the feedback and you have to look on it and adapt it […].” *(Participant 6)*

One participant is also afraid of the fact that he has to learn something new to apply self-management behavior.

*Quote 15:* “A change is not always an improvement. Sometimes, I think that then, I need to understand it again.” *(Participant 9)*

Another factor is that some of the patients want to be confronted with their disease as little as possible. They see self-management behavior as something that would increase their daily confrontation with their illness (n=4).
Quote 16: “I don’t know the type of COPD I have, actually, I also don’t want to know it. I never delved into this anymore. I am ill and I will stay ill and it is never going to be better again. [...] In the beginning I wanted to know everything. But the more I knew, the less comfortable I felt. At one point, I thought, that’s enough. (Participant 1)

4.5.2 Positive Attitudes

There are also participants who have positive attitudes regarding self-management behavior.

Five participants mention that a benefit of self-management behavior is that it might improve their well-being.

Quote 17: “This [using the inhalator in the right way] is of course much better for my health, because I feel better by this. And I maintain my fitness...” (Participant 2)

One participant says that it could reduce visits to the hospital.

Quote 18: “Yes, [she would use a device to support her self-management behavior], I think so, because using the medication adequately is really important. If not, you can become unnecessary short of breath, you get sick, or you have to go to the hospital, or whatever.” (Participant 6)

Two participants mention that self-management behavior, such as using the COPD coach, improves their feeling of safety. One participant mentions that self-management behavior would be time-saving and would improve his autonomy.

Quote 19: “It is time-saving and I don’t need to approach someone else for it.” (Participant 2)

4.6 The participants’ perceived subjective norm regarding self-management

In this sample, not all of the participants mention their thoughts about how others could evaluate self-management behavior. Two participants seem to perceive the subjective norm
regarding self-management as negative. All of these patients were female. Two male patients seem to perceive the subjective norm as positive.

4.6.1 Negative subjective norm

One participant describes that she would not use her inhalator in public at all. However, she does not give reasons why she would not use it.

*Quote 20:* “When I am in a foreign place, then, I don’t do it in public.” (Participant 8)

Furthermore, one participant describes that the time she needs for her inhalator use in the morning could also be used for preparing breakfast for her husband. Therefore, she seems to be afraid that her husband could experience a negative impact from her self-management behavior on his life. This results in a hurried and sometimes incorrect inhalator use.

*Quote 21:* “The hastiness [which results in incorrect use of her inhalator] [...] then, I think: my husband is getting out of bed and yes, it would be nice if the food and a cup of tea are ready by then.” (Participant 1)

4.6.2 Positive subjective norm

One patient mentions that using more self-management behavior could be evaluated positively by others, because he would be less of a burden to them.

*Quote 22:* “Yes, of course, yes, then, I wouldn’t have to ask others, if I do it right or wrong, at all anymore. That’s easy. Then, I don’t have to bother others anymore. (Participant 2)

Another patient describes that by trying new ways of handling his disease, he could give something back to the people that care for him.

*Quote 23:* “They always do so much for me, thus why shouldn’t I do something for them in return?” (Participant 7)
4.7 The participants’ perceived behavior control regarding self-management behavior

Five of the ten COPD patients state that they have no problems with using the inhalator correctly. Six participants perceive their behavior control regarding the preparation of the inhalator, before using it, as high.

Quote 24: “It goes well...I never forget a step, [...]. This is automatism.” (Participant 2)

Quote 25: “[Furthermore, all actions go well? Nothing, from which, you would say, this is difficult?] No, no, I don’t think it is difficult.” (Participant 6)

However, it is important to distinguish between perceived behavior control and actual behavior control. For example, one of the participants, who perceives her behavior control as high, mentions that she received negative feedback when she showed her inhalator use to a professional.

Quote 26: “I really thought that I do it right, that it works well. Well, it seemed that I did it [to inhale] way to strong. [...] That was what was shown.” (Participant 1)

There are also participants who report that they sometimes forget to use the inhalator (n=2), forget to clean it (n=6) or are not able to use the inhalator correctly (n=5).

Quote 27: “[Thus, sometimes you don’t do it as you have learned it to do?] No, sometimes, it goes wrong.” (Participant 8)

The participants mention different reasons for their inability to use the inhalator correctly. These are: shortness of breath (n=3), cough (n=3), hastiness (n=3) and forgetting the right instructions (n=2).

However, regardless of their perceived behavior control, all patients, except one, would like to receive feedback about their self-management behavior.
5. Discussion

First of all, it can be said that the participants perform behavior of the first and second level of self-management. Secondly, most participants hold negative attitudes regarding self-management. They perceive the personal, social and financial costs of self-management as high. The positive attitudes mentioned are mostly associated with an increased sense of well-being. The perceived subjective norm regarding self-management does not seem to play an important role for the participants. However, some participants acknowledge the influence which self-management behavior might have on their social environment. The perceived behavior control varies. The main reasons for not being able to use the inhalator correctly are the physical limitations of the participants.

In the following paragraph, it will be discussed how, based on the results of this research, COPD patients could be supported to develop onto a higher level of self-management. Therefore, the three most important findings and their scientific support will be examined. The results show that most of the participants use a smartphone (see Table 2). The recommendations will therefore be applicable for a smart-phone app, because an app can be easily used at any time of the day, for example while traveling by bus or waiting in line in the supermarket. An overview of all recommendations can be found in Table 5 (p. 33).

5.1 Three essential recommendations for an e-health technology to support self-management of COPD patients

First of all, the results show that many participants perceive the personal, social and financial costs of self-management as high. Therefore, to enhance self-management behavior, it is important to emphasize its numerical and personal benefits. This assumption can be supported
by the various psychological theories of cost reward analyses. Here can be mentioned: The Cost-Reward Model or the Expected Utility Model (Dovidio, Piliavin, Gaertner, Schroeder & Clark, 1991; Von Neumann & Morgenstern, 1947). These theories state that people decide if they perform an action based on a weighting of the costs and benefits of the action of interest. While the original theories mainly focus on costs and rewards in relationships, the research by Lindemeier (2008) indicates that perceived costs and benefits also play a role in the decision making process of whether to get involved in volunteer work or not. This means that the cost reward model can not only be used for the analysis of relationships, but also gives an indication of the decision-making process regarding the execution of a behavior of interest. This suggests that it could also be applied for self-management behavior.

Based on this knowledge, it might be assumed that if COPD patients know more about the benefits of self-management, their willingness to perform more self-management behavior might increase. Therefore, the recommendation for a self-management intervention is to implement education modules, where the benefits of self-management are explained and to provide peer support through an online chat with other users, where patients can talk about their personal experiences. By this, both numerical and personal benefits of self-management might be seen by doubting patients.

Secondly, the results indicate that patients fear that self-management would increase their daily confrontation with their illness and that this could influence their emotional well-being negatively. One example of a negative belief can be found in Quote 16 (p. 26). Therefore, it is important to strengthen the emotional well-being of the patients.

It has been shown that cognitive behavioral therapy can help to recognize generalized, negative beliefs and to convert them into more functional, positive beliefs (Dobson & Dozois, 2001 as cited in Courtois & Ford, 2009). The research by Kunik et al. (2008) showed that
CBT can improve the COPD patients’ quality of life, anxiety and depression. Positive effects of CBT on depression and anxiety in COPD patients could also be found in a smaller research by Hynninen, Bjerke, Pallesen, Bakke & Nordhus (2010). In the above mentioned research by Kunik et al. (2008) the CBT sessions for COPD patients involved techniques such as: education and awareness training, relaxation training, cognitive therapy and problem-solving techniques. Furthermore, the sessions involved group discussions and homework (Kunik et al, 2008). It should be taken into account that there might be differences between an online CBT intervention and face-to-face interventions.

The systematic review by McCombie, Geary, Andrews, Mikocka-Walus & Mulder (2015) evaluates the effectiveness of computerized CBT. The effects of computerized CBT were mixed. Nevertheless, no negative effects of computerized CBT were reported. Based on this information, the recommendation is to implement cognitive behavioral therapy modules in the e-health self-management intervention. The CBT modules could be implemented in the form of online CBT sessions by mental health clinicians.

Finally, the results demonstrate that half of the participants perceive their behavior control, regarding the correct inhalator use, as low. Therefore, it is important to help them develop skills that facilitate a correct inhalator use. It has been shown that inhalation skills education has a positive effect on the correct inhalator use of COPD patients (Sancar, Sirinoğlu, Okuyan, Karagöz & Izzettin, 2015).

Furthermore, it has also been shown that education regarding topics, such as airway management, use of oxygen, nutrition, exercise or smoking cessation have a positive effect on the quality of life of COPD patients (Kunik et al., 2008). The adoption of the same topics were also recommended by Effing et al. (2012). Next to these topics, Effing et al. (2012) recommended to address the recognition and treatment of exacerbations, for example, through
self-treatment action plans. Other topics that were found to be important from the patient perspective are: symptom management, activity and exercise implementation, environmental control, emotional adaptation and maintaining a healthy lifestyle (Chen, Chen, Lee, Cho & Weng, 2008). The research by Burkow et al. (2015) indicates that online group education sessions and online educational videos for COPD patients reduce their impairment of quality of life. Therefore, the recommendation is to implement videotaped education and skills training modules.
### Table 5.

**Recommendations for an e-health self-management intervention**

<table>
<thead>
<tr>
<th>Results</th>
<th>Strategies to support self-management</th>
<th>Suggestions for the implementation in e-health intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negative attitudes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too expensive</td>
<td>-design a device that can be implemented in technology most people have</td>
<td>-an app that can be downloaded on every smartphone for free</td>
</tr>
<tr>
<td>No benefits</td>
<td>-show statistical and personal benefits</td>
<td>-peer support through online chat with other COPD patients: users can send other users a friend request and as soon as accepted, can online chat with them</td>
</tr>
<tr>
<td>Not able to acquire required skills/knowledge</td>
<td>-provide education and practical skills training</td>
<td>-videotaped lessons and skills demonstration by a professional</td>
</tr>
<tr>
<td>Labor intensive</td>
<td>-provide suggestions for an easy implementation in everyday life</td>
<td>-pop up of suggestions for everyday use: to reassure the suitability of the suggestions, the patient has to fill in a short questionnaire where he has to indicate his current stage of COPD before he can start using the app</td>
</tr>
<tr>
<td>Time consuming</td>
<td>-implement cognitive behavioral therapy</td>
<td>-online CBT sessions by mental health clinicians</td>
</tr>
<tr>
<td>Increases confrontation with illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Positive attitudes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling of safety</td>
<td>-increase feeling of safety</td>
<td>-emergency button</td>
</tr>
<tr>
<td><strong>Subjective norm</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deprivation of time for relatives</td>
<td>-education for relatives</td>
<td>-also non-COPD patients should be able to download the app and get connected to patients</td>
</tr>
<tr>
<td>-Negative evaluation by general public</td>
<td>-feedback by relatives</td>
<td>-particular education modules for non-COPD patients</td>
</tr>
<tr>
<td>-Raise public awareness for COPD</td>
<td></td>
<td>-short message device for relatives to send feedback</td>
</tr>
<tr>
<td><strong>Behavior control</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feedback is desired</td>
<td>-inhalator usage reminder</td>
<td>-self-management behavior can be filmed (use smartphone camera) and send to a professional</td>
</tr>
<tr>
<td>Forgetting inhalator use</td>
<td>-self-management behavior can be filmed (use smartphone camera) and send to a professional</td>
<td></td>
</tr>
<tr>
<td>Forgetting the amount of medication dosage taken</td>
<td>-medication dosage counting function</td>
<td>-transmission from counting function from inhalator to the app, notification of the current dosage number</td>
</tr>
</tbody>
</table>
5.3 The social aspect of self-management

The main challenge that became noticeable during this analysis is that many of the participants hold negative attitudes regarding self-management. They do not seem to be ready for a change in their health care process. This raises the question, why patients are not willing to make a change. One important effect of self-management interventions is a decrease in hospital admissions (Lorig et al., 1999; Adams et al., 2007). This is evaluated as positive by researchers and health care experts for resulting in a decline of healthcare costs (Adams et al., 2007), but it might be evaluated negatively by the patients themselves. One aspect that might be important for patients is that visits to a doctor or hospital provide social interaction. For a visit to the doctor, patients leave their house, travel to the medical practice, talk to a doctor’s assistant, maybe wait in the waiting room with other patients and finally, meet the doctor. All of this is an interruption to the daily routine and provides possibilities for social encounters. Four percent of 1670 Dutch participants between 60 and 74 years report severe loneliness (Scharf & de Jong Gierveld, 2008). This is of particular importance for COPD patients, because COPD is most often diagnosed in people aged 55 and older and the prevalence increases with age (RIVM, 2014). Ellaway, Wood, & Macintyre (1999) examined the connection between loneliness and frequency of visits to the doctor for 691 participants. The results were controlled for socioeconomic status, sociodemographic variables and health. It shows that loneliness is significantly associated with the frequency of visits to the doctor. Respondents who reported to feel lonely ‘most of the time’ or ‘often’ had almost twice as many visits to the doctor than respondents who reported to feel lonely ‘rarely’ or ‘never’ (Ellaway, Wood & Macintyre, 1999). Based on this, it seems necessary that social aspects are taken into account while developing an e-health intervention.

In the recommendations for an e-health intervention that are given here, the social aspect is addressed by online chats with peers. However, it is questionable to what extent this
is sufficient. Perhaps the social support has to be given more emphasis in daily life, in addition to the e-health technology. This could be done by providing more social activities or creating community organizations in neighborhoods for the COPD patients to attend. If patients would not feel the need to visit a doctor for social interaction, because their needs for social interaction were met in a different way, they might be more open towards changes in the health care process.

5.4 Limitations

Regarding the methodological limitations of this research, it can be said that the greatest problem was the adaption of data that was originally gathered for a different purpose. As the data was originally gathered for research aimed at the evaluation of inhalator use, not many questions were particularly directed at self-management behavior. Therefore, it was sometimes necessary to read between the lines, which made it difficult to keep the analysis truly objective and researcher independent. To keep this influence as low as possible, clear definitions for every code were given. Furthermore, to increase the transparency of the analysis, Cohen’s Kappa has been calculated.

6. Conclusion

Summarizing, it can be said that this research demonstrates that the development of an e-health self-management intervention is important, because currently most of the participants only perform behavior of low levels of self-management. The results of this research contribute to the field of e-health by presenting three recommendations for the development of an efficient e-health self-management technology. These are: peer support through online chats, online CBT sessions and education and skills training modules. Further research is necessary to evaluate the effectiveness of the application of these recommendations in an
actual e-health device. This research differs from other research projects in the field of e-health, because it provides qualitative, personal information about the potential users of an e-health self-management intervention and their social and behavior values. Therefore, it contributes to the development of an effective intervention by providing information for the steps ‘Contextual Inquiry’ and ‘Value Specification’ of the CeHRes Roadmap (van Gemert-Pijnen, 2011). The generalizability of the results has to be considered carefully. However, the research gives insight in the personal thoughts of the participants. It provides input for the development of e-health technology that takes into account the individual aspirations and worries of COPD patients.
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## Appendix

### Quotes

<table>
<thead>
<tr>
<th>Quotes in Dutch</th>
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| “[Op welke manier denkt u geholpen te kunnen worden zodat u de instructies voor het gebruiken van de inhalator elke keer juist kunt uitvoeren?]” Dat is een goeie.. daar kan ik even geen antwoord op geven. Nee dat weet ik niet..” | Quote 1 “[In what way do you think you could be supported to execute the instructions for using the inhalator every time in the right way?] That is a good one… I cannot give an answer on that right now.
No, I do not know this.” (Participant 1) |
| “Ten eerste krijgen wij dus altijd een uitgebreide informatie brief mee van de apotheek waarop staat wat ik neem en hoe vaak het moet.. maar dit zijn geen instructies van hoe het moet. Maar ik ben niet zo’n computer man.. maar je zou dit bijvoorbeeld via de computer op kunnen zoeken. Maar dat doe ik eigenlijk nooit.” | Quote 2 “Firstly, we always get a detailed information letter from the pharmacy, on which is written what I take and how often I have to take it… but there is no instruction on how I have to take it. But I am not such a computer-savvy person, for example you could search this via the computer. But I do this hardly ever.”(Participant 3) |
| “[Stel dat u meer zou willen weten over het gebruiken van uw inhalator, waar zou u dan informatie zoeken? ] Dan zou ik eerst bij de huisarts informatie zoeken en bij de longassistente.” | Quote 3 “[Imagine that you would like to know more about the use of your inhalator, where would you search for information?]
Then, I would ask the doctor for information and the nurse practitioner.”(Participant 5) |
<p>| “[Stel u krijgt een aanval en u voelt zich | Quote 4 “[Imagine you get an attack and |</p>
<table>
<thead>
<tr>
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<tr>
<td>“Daarnaast kijk ik wel eens op de website voor informatie en daarnaast is er ook een forum en daar kijk ik wel eens op.”</td>
<td>Next to that, I look on the website for information and there is also a forum, which I use sometimes.” (Participant 6)</td>
</tr>
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<td>“En tot slot is dit nog een extra puf voor als ik benauwd ben dus echt voor noodgevallen.”</td>
<td>And finally, I have an extra inhalator. I use it when I am really short of breath, thus really in emergencies.” (Participant 2)</td>
</tr>
<tr>
<td>“Je kunt steeds minder en ja dan zoek je steeds in een andere hoek iets op om wat te kunnen doen.”</td>
<td>“You are less and less able to do things, so you keep searching in different corners to find something you are able to do.” (Participant 7)</td>
</tr>
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<td>“Je moet uitkijken dat je niet geïrriteerd raakt door het feit dat bepaalde dingen wel eens niet lukken.”</td>
<td>“You have to look out for yourself, so that you don’t get upset through the fact that some things sometimes just don’t work.” (Participant 8)</td>
</tr>
<tr>
<td>opeens extreem benauwd. Wat kan u helpen om zo snel mogelijk en op de juiste manier te inhaleren zodat u zich gauw minder benauwd voelt?]</td>
<td>suddenly feel extreme short of breath. What would help you to inhale, as fast as possible and also using the right method, so that you would feel less short of breath soon?]</td>
</tr>
<tr>
<td>Ja proberen rustig te blijven, dat ik punt één dus niet in paniek raken. Dat is mij ook wel eens overkomen en ook wel eens dat ik daarna de dokter belde. Het typische is dit soort dingen gebeuren heel vaak in het weekend als de reguliere dokter er niet is.”</td>
<td>To try to stay relaxed, so that firstly, I won’t panic. This also happened to me in the past, and also once that I called the doctor afterwards. Typically, these kinds of things happen at the weekend, when the regular doctor isn’t there. “ (Participant 9)</td>
</tr>
<tr>
<td>“Daarnaast kijk ik wel eens op de website voor informatie en daarnaast is er ook een forum en daar kijk ik wel eens op.”</td>
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<td>“You have to look out for yourself, so that you don’t get upset through the fact that some things sometimes just don’t work.” (Participant 8)</td>
</tr>
<tr>
<td>“Ik mocht het dus zelf regelen en dan moest je dus je pufjes gaan verhogen en dat moet je dan ook niet gaan vergeten.”</td>
<td>“I was allowed to self-manage it [her medication] and then, you had to increase your inhalator use and you were not allowed to forget that.” (Participant 10)</td>
</tr>
<tr>
<td>“Als ik het echt benauwd heb dan doe ik het overdag ook wel eens. Want ik ben zelf baas en de dokter voelt dit niet maar ik wel.”</td>
<td>“If I am really short of breath, than I also take one [medication] during the day, because I am the boss and the doctor does not feel this, but I do.” (Participant 9)</td>
</tr>
<tr>
<td>“Ik heb op mijn telefoon een app en die gebruik ik om te tellen zodat ik het aantal kan bijhouden. [Oké, en is dit een speciale app voor het medicatie gebruik?] Nee, maar als je die zou kunnen laten uitvinden. Nee deze is voor in de bar om te tellen hoeveel drankjes iedereen heeft. Maar dit is de enige app die ik kon vinden om iets te tellen.”</td>
<td>“On my phone I have an app and I use it to count [the medication use], so that I can remember the amount. [Okay, and is this a particular app for the medication use?] […No, this one is actually, to tell how many drinks everyone had in a bar. But it was the only app I could find to count something.” (Participant 6)</td>
</tr>
<tr>
<td>“Nee, ik zie het nut er niet zo van in. Want het is al jaren goed gegaan.”</td>
<td>“No, I don’t see the benefits of this, because it went well like this all those years.” (Participant 1)</td>
</tr>
<tr>
<td>“Daar heb ik helemaal geen zin in. Er zijn ook”</td>
<td>“I really don’t want to do this”</td>
</tr>
<tr>
<td>Quote 14: “[…] I think it [the proposed self-management behavior] would cost once again extra time, because you get the feedback and you have to look on it and adapt it […]” (Participant 6)</td>
<td>Quote 15: “A change is not always an improvement. Sometimes, I think that then, I need to understand it again.” (Participant 9)</td>
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<td>“Nee want ik denk dat dit ook wel weer extra tijd gaat kosten want je krijgt die feedback en daar ga je ook naar kijken en doen en dan maak je het misschien ook wat omslachtiger het inhaleren.”</td>
<td>“Maar niet altijd is een verandering een verbetering. Dan denk ik ook wel eens dan moet ik het weer snappen.”</td>
</tr>
<tr>
<td>“Het type COPD wat ik heb weet ik niet en wil ook eigenlijk ook niet weten. Hier heb ik mij verder nooit meer in verdiept. Ik ben ziek en ik blijf ziek en het wordt nooit meer beter. Wat moet ik er verder mee. In het begin wou ik alles weten. Maar hoe meer je weet hoe minder prettig ik mij voelde. Ik dacht op een gegeven moment laat maar.”</td>
<td>“Dat is voor mijn gezondheid natuurlijk veel</td>
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<td>Translation</td>
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<tr>
<td>„Ja ik denk het wel want het is gewoon heel belangrijk dat jij je medicijnen goed binnen krijgt want anders wordt je misschien onnodig benauwd, wordt je ziek of raak je in het ziekenhuis of wat dan ook.”</td>
<td>“Yes, [she would use a device to support her self-management behavior], I think so, because using the medication adequately is really important. If not, you can become unnecessary short of breath, you get sick, or you have to go to the hospital, or whatever.” (Participant 6)</td>
</tr>
<tr>
<td>“Het is tijdbesparend en ik hoef anderen niet te benaderen.”</td>
<td>“It is time-saving and I don’t need to approach someone else for it.” (Participant 2)</td>
</tr>
<tr>
<td>“Als ik in de vreemde of ergens ben dan doe ik het toch niet in het openbaar.”</td>
<td>“When I am in a foreign place, then, I don’t do it in public.” (Participant 8)</td>
</tr>
<tr>
<td>“De haastigheid en eh ja. Ja het is even anders en ja ik weet het niet dan denk ik mijn man komt uit bed en ja het is fijn als dan het eten klaar staat en een kopje thee klaar staat.”</td>
<td>“The hastiness [which results in incorrect use of her inhalator] […] then, I think: my husband is getting out of bed and yes, it would be nice if the food and a cup of tea are ready by then.” (Participant 1)</td>
</tr>
<tr>
<td>“Ja zeker, ja dan hoef ik al helemaal niet meer te vragen aan anderen of ik het wel of niet goed doe. Dat is wel makkelijk. Ik hoef</td>
<td>“Yes, of course, yes, then, I wouldn’t have to ask others, if I do it right or wrong, at all anymore. That’s easy. Then, I</td>
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<tr>
<td>Dutch</td>
<td>English</td>
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<td>anders dan niet meer lastig te vallen.”</td>
<td>don’t have to bother others anymore. (Participant 2)</td>
</tr>
<tr>
<td>“ Ze doen ook altijd zoveel voor mij dus waarom zou ik niet wat voor</td>
<td>Quote 23: “They always do so much for me, thus why shouldn’t I do something for them in return?” (Participant 7)</td>
</tr>
<tr>
<td>hen terug kunnen doen.”</td>
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<tr>
<td>“Dus dit gaat goed.. ik vergeet nooit een stap want dit zit erin</td>
<td>Quote 24: “It goes well… I never forget a step, […] This is automatism.” (Participant 2)</td>
</tr>
<tr>
<td>gehamerd. Dit is automatisme.”</td>
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<tr>
<td>“Gaan verder alle handelingen goed? Niet iets waarvan u zegt dit is</td>
<td>Quote 25: “[Furthermore, all actions go well? Nothing, from which, you would say, this is difficult?] No, no, I don’t think it is difficult” (Participant 6)</td>
</tr>
<tr>
<td>moeilijk? Nee, nee ik vind he niet zo moeilijk…”</td>
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<tr>
<td>“Ik dacht echt van dat doe ik wel goed, dus dat zit wel goed. Nou,</td>
<td>Quote 26: “I really thought that I do it right, that it works well. Well, it seemed that I did it [to inhale] way to strong. […] That was what was shown.” (Participant 1)</td>
</tr>
<tr>
<td>wat bleek nu dus is dat bij mij het ging veel te krachtig en dus</td>
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<tr>
<td>dat klapte in een keer weg en nou dat is daar uitgekomen […].”</td>
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<tr>
<td>“[Maar dus soms gaat het niet helemaal zoals u geleerd hebt om het</td>
<td>Quote 27: “[Thus, sometimes you don’t do it as you have learned it to do?] No, sometimes, it goes wrong” (Participant 8)</td>
</tr>
<tr>
<td>te doen?] Nee dat mislukt wel eens een keer.”</td>
<td></td>
</tr>
<tr>
<td>“[Zou u het bijvoorbeeld fijn vinden om terugkoppeling/informatie te</td>
<td>Quote 28: “[Would you like to receive feedback/information about the correctness of your inhalator use?] Yes, I would like to”</td>
</tr>
<tr>
<td>krijgen over of u de inhalator goed hebt gebruikt? ]</td>
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Ja ik wil graag geïnformeerd worden daarover. “

“[…]de telefoon zit altijd in mijn tas ik heb hem altijd bij mij. Dus via de telefoon is informatie ontvangen een goede manier.”

get informed about that.” (Participant 2)

Quote 29: “The phone is always in my bag, I have it always with me. Therefore, it would be a good way, to get information via the phone.” (Participant 1)