The experience of individuals with COPD and their families of the disease at its beginning stages
An interpretive phenomenological study

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Abstract

Chronic Obstructive Pulmonary Disease (COPD) often progresses for years with insidious decline in lung function. Adjustment to symptoms in daily life is gradual and the disease is often moderately advanced when healthcare is finally sought.

The purpose of this study is to gain insight into the experience of living with COPD at beginning stages; how persons come to terms with the disease, how symptoms develop, manifest and affect life as a whole. The research question is: How do individuals with COPD and their families experience the disease at its beginning stages?

The methodology used was interpretive phenomenology. Participants had already finished participation in an intervention study on individuals with COPD, stage II and III and their family members: Partnership to enhance self-management of people with COPD and their families. In continuation to the intervention study further data was collected through four family-focus group interviews (n=34) and a subsample of eight families. Data from both family interviews and focus groups are the data of this study.

Results were analyzed into five not mutually exclusive themes;

“Self-inflicted”, shameful disease
Enclosed in addiction
Living in parallel worlds – patients and family members
Needing to get to the “end of the rope” before realizing the disease
A call for sympathy and hope

It is concluded that patients and families need a maintained support to be able to manage the disease, accept its existence and deal with the challenge of addiction and shame. This support must be provided as early in the disease process as possible in order to delay its progress.
Keywords: COPD, beginning stages, families, interpretive phenomenology.
Útdráttur

Langvinn lungnateppa (LLT) er sjúkdómur sem þróast á mörgum árum. Einkennin eru lúmsk og læðast gjarnan aftan að einstaklingnum sem aðlagast þeim smátt og smátt í daglegu lífi. Sjúkdómurinn hefur gjarnan þróast á meðalslæmt eða alvarlegt stig þegar kemur að því að leita sér aðstoðar heilbrigðisþjónustunnar.

Tilgangur rannsóknarinnar er að öðlast innsýn í þá reynslu að lifa með LLT á byrjunarstigi, hvernig einstaklingar áttu sig á tilvist sjúkdómsins, og hvernig einkenni birtast og hafa áhrif á lífið í heild. Rannsóknarspurningin er: Hvernig upplifa einstaklingar með LLT og fjölskyldur þeirra sjúkdóminn á byrjunarstigi?

Áþferðafræðin er túlkandi fyrirbærafræði. Þátttakendur höfðu þegar lokið þátttöku í meðferðarrannsókn á einstaklingum með LLT, stig II og III og fjölskyldumeðlíminum, Efting heilbrigðis- og sjálfsúrnunar hjá fólki með langvinna lungnateppu og fjölskyldum þeirra. Í framhaldi af meðferðarrannsókninni var frekari gagna aflað með fjórum rýnihópum (n=34) og úr rýnihópunum valið úrtak áttá fjölskylda og tekin viðtöl. Rannsóknargögnin, bæði fjölskylduvíðtölin og rýnihópaviðtölin, voru þemagreind.

Niðurstöður eru greindar í fimm þemu sem að einhverju leyti skarast:

*Sjálfskapadur, skammarlegur sjúkdómur*

Fjöutraður í fíkn

Að lifa í aðskildum heimum

Að skilja ekki fyrr en skellur í tönnun

Ákall um skilning og von

Í kjölfar niðurstaðna er ályktað að einstaklingar með LLT og fjölskyldur þeirra þurﬁ mikinn stuðning til þess að geta tekist á við sjúkdóminn, áttuð sig á tilvist hans og tekið á vanda fíknar og skammar. Því fyrir í sjúkdómsferlingu sem
sá stuðningur er veittur því meiri möguleikar skapast til að hægja á framgangi sjúkdómsins.

Lykilorð: Langvinna lungnateppa, byrjunarstig, fjölskyldur, túlkandi fyrirbærafræði.
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Introduction

This study is a part of an intervention study on individuals with COPD, stage II or III and their family members, *Partnership to enhance self-management of people with COPD and their families*, led by Professor Helga Jónsdóttir and her research team. The purpose of the present study is to gain insight into the experience of living with COPD at beginning stages; how persons come to terms with the disease, how symptoms develop, manifest and affect life as a whole. The research question is: How do individuals with COPD and their families experience the disease at its beginning stages?

COPD is characterized by persistent and progressive airflow limitation associated with enhanced chronic inflammatory response in the airways to smoke or noxious gases. Narrowing of the small airways leads to a decrease in lung elastic recoil. Smoking is the main risk factor for developing COPD but other factors can also play a part (GOLD, 2013). The disease has been growing in prevalence and is predicted to continue to grow in coming decades (GOLD, 2013). A spirometry test is necessary to diagnose the disease and divide it into grades according to severity. Underdiagnosis is common but may be countered by greater efforts to screen at-risk individuals (GOLD, 2013; Hill et al., 2010). Symptoms like breathlessness, chough and sputum production are not always in context with airflow limitation (Sutherland & Chermiack, 2004).

Individuals with COPD are likely to be stigmatized because of their smoking and they experience self-blame and contempt from others (Berger, Kapella & Larson, 2011; Arne, Emtner, Janson & Wilde-Larsson, 2007). Cigarette smoking is highly addictive as nicotine delivers quickly to the brain and high amounts of nicotine are attained in the brain from smoking. These two crucial factors promote and sustain nicotine addiction along with social and psychological factors as well (Tønnensen et al., 2007; Dome, Lazary, Kalapos & Rihmer,
Smoking cessation for people with COPD has been disappointingly unsuccessful and people with COPD do not always relate the progression of the disease to smoking (Wagnea, van der Meer, Ostelo, Jacobs & van Schayck, 2004). People with COPD tend to delay seeking medical help (Arne, Emtner, Janson & Wilde-Larsson, 2007; Halding, Heggdal & Wahl, 2011). The most commonly used approach in management of COPD is self-management. Conceptualization and the effectiveness of self-management programs are disappointing (Jónsdóttir, 2013).

The purpose of this study is to describe the experience of living with COPD at its beginning stages. Interpretative phenomenology was considered the most appropriate method to use for this purpose. Patients in the intervention study were originally recruited from primary health care centers and physicians’ offices and had by the time this study started finished that study which was a one year intervention program. In continuance, data was collected through four family-focus group interviews (n=34) and a subsample of eight families. Data from both the family interviews and focus group interviews are the data of this study. The interviews were transcribed verbatim and analyzed with thematic analysis (Benner, 1994).

The author has cared for patients with COPD for some years and questions have developed about why people tend to delay seeking medical assistance and find it difficult coming to terms with the disease even at an advanced stage where they sometimes still deny its existence. Studies on the experience of coming to terms with the disease at its beginning stages are rare. The author hopes that this study will increase in understanding of what COPD means for individuals and their families and suggests approaches to health care which might be helpful in assisting people to come to terms with the disease which might, consequently, delay the progression of the disease and bring it to a halt in the most successful cases.
Research question

This study aims to answer the following research question: How do individuals with COPD and their families experience the disease at its beginning stages?
Literature review

In this chapter the disease Chronic Obstructive Pulmonary Disease (COPD) will be described in terms of epidemiology, diagnosis, symptoms and development. Means of self-management will be explained and people’s experience of stigmatization and shame explored as well as addiction and smoking.

_Chronic obstructive pulmonary disease_

This study deals with the experience of living with chronic obstructive pulmonary disease at its beginning stages. The definition of the disease, epidemiology, symptoms and effects on people’s lives will be explored.

The definition of the disease is taken from the Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2013) which is a global teamwork of scientists who have made an effort to increase awareness of COPD and have composed global strategies for the diagnosis, management and prevention of the disease based on scientific evidence. According to that definition COPD is characterized by persistent airflow limitation which is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lungs because of noxious particles or gases. This chronic inflammation causes structural changes and narrowing of the small airways which leads to a decrease in lung elastic recoil and diminution of the airways ability to remain open during expiration (GOLD, 2013; Phipps, Monahan, Sands, Marek & Neighbors, 2003).

The primary risk factor for developing COPD is smoking although nonsmokers may also develop chronic airflow limitation. Smokers generally have a higher prevalence of respiratory symptoms and decline in lung function. Passive exposure to cigarette smoke can also increase the risk. A Danish research revealed that the absolute risk of developing COPD among continuous smokers is at least 25% (Løkke, Lange, Scharling, Fabricius & Vestbo, 2008). Genetic predisposition affects the risk of developing COPD as not all smokers, even with the same smoking history, will develop COPD. Risk factors, in addition to
smoking, which have been associated with reduced lung function are genes (deficiency of alpha-1 antitrypsin), lung growth development, socioeconomic status, asthma, childhood respiratory infection, age, gender and exposure to particles like dust, chemicals, indoor pollution, urban pollution and more (GOLD, 2013).

**Epidemiology**

COPD is the fourth leading cause of death in the world and the burden of the disease is predicted to grow in coming decades (GOLD, 2013; Benediktsdóttir, Guðmundsson, Jörundsdóttir, Vollmer & Gíslason, 2007). An Icelandic research has shown a high prevalence of COPD in the population among 40 years and older. The mean prevalence of people with grades I and higher was 18% of the population, thereof 9% were at grade II and higher (Benediktsdóttir et al., 2007).

Prevalence of the disease grows rapidly with advanced age and among those who have smoked much. Overall the disease is equally common among men and women but more young women than men have the disease, which, among with other things, indicates that smoking is more dangerous to women than men (GOLD, 2013; Løkke et al., 2006). COPD is one of a few diseases which has continued to grow in prevalence for decades and is predicted to grow even more and result in growing morbidity, mortality, drug costs and as a burden for the health care system. Now, as generations of heavy smokers (people born between 1950 and 1965) are growing older, and are near a certain age when the disease has growing effects on people’s health, an increased burden on the health care system is expected (Gulsvik, Boman, Dahl, Gislasson & Nieminen, 2006; Benediktsdóttir et al., 2007).

**Diagnosis**

Spirometry to test lung function and measure airflow limitation is required to diagnose COPD. Airflow limitation is measured by the rate between forced expiratory volume in one second (FEV1) and forced vital capacity (FVC). The
presence of a post-bronchodilator FEV1/FVC < 0.70 confirms the presence of COPD. The disease is divided into grades based on the spirometric classification of airflow limitation (recently GOLD exchanged the term stage to grade). GOLD grade II is moderate airflow limitation when FEV1 is between 50-80% of predicted value and GOLD grade III is severe airflow limitation when FEV1 is between 30-50% of predicted value based on age, gender and ethnic background. In recent years the emphasis on using only spirometry to diagnose the disease has decreased and now it is recommended that in any patient who has dyspnea, chronic cough or sputum production and/or history of exposure to risk factors of the disease a clinical diagnosis should be considered (GOLD; 2013).

COPD is commonly underdiagnoesd and the disease has often developed to a severe stage when diagnosed (Lindberg, Bjerg-Bäcklund, Rönmark, Larsson & Lundbäck, 2006; GOLD, 2013; Bednarek, Marciejewski, Wozniak, Kuca & Zielinski, 2008). According to the Icelandic study mentioned earlier only 8.3% of those who fulfilled the criteria for the disease had previously been diagnosed by a physician (Benediktsdóttir et al., 2007). In a primary health care in Canada only about 33% of those who fulfilled the criteria to have COPD were aware of their diagnosis before the study (Hill et al., 2010).

Underdiagnosing can be countered by greater screening of at-risk individuals in the primary health care (Hill et al., 2010; Bellamy & Smith, 2007; Radin & Cote, 2008) but the issue might be more complex than that. Persons with COPD often underestimate their symptoms as they commonly accept their symptoms as part of ageing or as a consequence of smoking and are therefore less likely to report symptoms, and that may play a part in the apparent underdiagnosis of the disease (Bellamy & Smith, 2007). COPD progresses for many years and the decline in lung function develops insidiously so persons often unconsciously reduce or adjust their lives to accommodate their respiratory symptoms. They usually do not seek medical help until they experience symptoms which affect their daily life, get exacerbation of their symptoms or have chronic symptoms. At
that point the disease is often moderately advanced (GOLD, 2013; Sutherland & Chermiack, 2004). Patients experience the diagnostic process as a prolonged one (Arne et al., 2007). Airflow limitation can be partly reversible and treatment of COPD can improve patient symptoms, quality of life, exercise capacity, health status and prevent exacerbations. Therefore it is essential to diagnose and treat the disease as early as possible (Radin & Cote, 2008; GOLD, 2013).

**Symptoms and onset of the disease**

Chronic and progressive dyspnea, chronic cough and sputum production are typical symptoms of COPD. Dyspnea is the main symptom of the disease and usually described as a sense of increased effort to breathe, heaviness or air hunger. Dyspnea is the major cause of disability associated with the disease. It progresses from affecting a few aspects, e.g. people notice they have difficulty walking at the same speed as their peers, to a point where dyspnea affects every part of daily life like dressing or walking a few meters and leading to a loss of social activity. An exacerbation is when symptoms acutely worsen beyond normal day-to-day variations, usually caused by respiratory infections which often lead to hospitalization (GOLD, 2013). Advanced disease is characterized by periods of stability and periods of exacerbations alternately and growing in frequency until the last exacerbation leads to death (Murray, Kendall, Boyd & Sheikh, 2005). Anxiety and depression are common with COPD and the disease often causes fatigue, weight loss and skeletal muscle dysfunction. Other frequent co-morbidities are cardiovascular diseases, osteoporosis and lung cancer, all of which can occur in patients with mild, moderate and severe airflow limitation (GOLD, 2013). Isolation and being closed in have been used to characterize the experience of COPD when life centers upon breathing and difficulties in expressing oneself and relating to others dominate (Jonsdottir, 1998).
The onset of symptoms is not always in context with airflow limitation. Sutherland and Chermiack (2004) made a descriptive graph which reveals the decline in lung function in patients with COPD in accordance to symptoms, see Figure 1. This figure shows that symptoms often do not appear until significant airflow limitation has developed; FEV1 has fallen to approximately 50% of the predicted normal value and from that point symptoms progress rapidly from mild to severe. This underlines the importance of early detection of the disease.

**Figure 1.** Deterioration in lung function in patients with COPD (Sutherland & Chermiack, 2004).

Although symptoms like coughing, wheezing and moments of difficulty breathing are present they are initially not recognized by the patient as signs of a disease. On top of that patients adapt to symptoms by avoiding or giving up physical activities or adjusting by slowing down the speed of activities.
Symptoms might be neglected and cough in the morning becomes a habit. Patients tend to hide their symptoms and delay seeking medical advice (Arne et al., 2007). What is known about people’s experience of the beginning stage of COPD is mainly based on studies of people with the disease at an advanced stage. Only a few studies were retrieved which studied individuals with beginning stages (stage I and II).

**Stigma and shame**

Stigma is defined as discrediting another; the person experiences social disapproval and discrimination because of characteristics which differentiate him/her from others in a way which reflect widely held social beliefs about personality, behavior and illness. Stigma may entail changes in body image, social isolation, rejection and more (Lubkin & Larsen, 2013).

Individuals with COPD are likely to be stigmatized because the disease is considered to be self-inflicted and, therefore they are less worthy of help. COPD is in most cases a result of many years of smoking and people’s response to a person with COPD can be affected by that. Family, friends and sometimes strangers make a connection between COPD and the self-imposed behavior of smoking which can contribute to self-blame. “Smoke-free” regulations may proceed in smokers being seen as less favorable (Lubkin & Larsen, 2013; Berger, Kapella & Larson, 2011). The response of health professionals towards the person with COPD might also be affected by the knowledge of the connection between smoking and COPD (Berger et al., 2011).

Smokers experience enacted stigma which refers to the situational response of others to behaviors or attribute of another (Lubkin & Larsen, 2013). In public places persistent cough and episodes of dyspnea draws the attention of others and the situation can be embarrassing as well as upsetting for both onlookers and the individual. As symptoms of the disease gradually become more difficult to
conceal the individual is likely to withdraw from uncomfortable situations and there-of become isolated (Berger et al., 2011). Persons with COPD often blame themselves for their behaviors which may have led to their disease and family members blame the person also because she/he smoked (Plaufcan, Wamboldt & Holm, 2012).

Stigma increases feelings of shame which can hinder people from seeking medical advice or from taking action to change their behavior (Arne et al., 2007). To face the fact that one has a smoking-related disease can be overwhelming and physicians’ “preaching” about abstinence from smoking can be counter effective (Jonsdottir & Jonsdottir, 2007). Persons with COPD feel that they are defined by the fact that they smoke or have smoked. Frequently health care professionals think the person who smokes and develops COPD should have known the risk and therefore he/she is responsible for his/her health at the present time (Berger et al., 2011; Lubkin & Larsen, 2013). Instead of reacting to individuals with COPD by stereotyping and/or with judgment patients often wish their personal stories would be listened to and how their disease has developed in their own life. That way, their personal story would get more attention and risk factors in their life in addition to smoking, e.g. their unhealthy workplaces or passive smoking in their childhood, might be included in possible explanation for the disease (Bailey, Montomery & Boyles, 2009).

**Addiction and smoking**

Cigarette smoking is the major risk factor for development and progression of COPD and quitting smoking the most important action to stop or delay the progression of the disease (GOLD, 2013; Tønnesen et al, 2007).

A person with COPD has a more urgent need to stop smoking than the average smoker but often finds it more difficult to do so. The most likely reason is nicotine dependence as that is the underlying mechanism responsible for
persistent tobacco use although psychological factors and habituation also play a role. Moreover, smokers with COPD seem to have a higher dependence on nicotine than other smokers (Tønnesen et al, 2007). Smoking is categorized as a disease of addiction in the *International Classification of Diseases* (ICD -10) and the American *Diagnostic and Statistical Manual and Mental Disorders* (DSM-IV) (ICD10Data.com, 2013; Jónsdóttir et al., 2009). Cigarettes are addictive and nicotine is the drug in tobacco which causes addiction. Tobacco addiction is considered of similar strength as addiction to drugs, such as heroin and cocaine (U.S. Department of Health and Human Services, 2010).

Nicotine addiction is complex and characterized by multiple factors; physiological, social and psychological which promote persons to continue smoking (Blöndal, 2007). The rapid rate of nicotine absorption and high amounts of nicotine attained in the brain from smoking are two crucial factors which promote and sustain nicotine addiction. Cigarettes deliver nicotine quickly and smoking is the most harmful form of nicotine consumption. Once cigarette smoke is inhaled nicotine immediately reaches the lungs and passes the bloodstream to the brain. Nicotine has diverse effects on various brain functions, influences the activity of several neurotransmitter systems and has even been linked to functional and structural changes in the brain (Dome, Lazary, Kalapos & Rihmer, 2010). Once in the brain, nicotine binds to receptors which release dopamine and activate the so called reward system which gives the smoker the pleasure he/she craves for. This has been called the positive reinforcement. Negative reinforcement however refers to a process by which nicotine reduces negative-affect states such as pain, craving, difficulty concentrating, irritability, depression symptoms and more. With continued use of cigarettes over time the receptors in the brain increase and in abstinence from smoking the smoker experiences a series of those negative-affect states which wear off as he/she smokes again. In addition, environmental learning process is when smoking cues are connected to certain things in the environment and a strong habit is created.
Smoking is not simply a lifestyle or a choice of the addicted smoker (Blöndal, 2007). About 4-12 hours after quitting smoking varied withdrawal symptoms begin to appear such as irritability, anxiety, restlessness, difficulty concentrating, craving for cigarettes and more (U.S. Department of Health and Human Services, 2010). The knowledge of the harm smoking can do and the wish to stop it conflicts with the addiction and despite the smoker’s good intentions, the addiction prevails. Smoking gets an unhealthy priority beyond the wish to stop it (Blöndal, 2007; Lindqvist & Hallberg, 2010). Smokers have described this as striving for freedom from the cigarettes they know are not good for their health, but at the same time smoking gives a temporal feeling of freedom and calms difficult feelings so the urge to smoke is hard to resist (Jonsdottir & Jonsdottir, 2007).

The effectiveness of smoking cessation interventions for people with COPD has shown disappointingly low success (Wagena, van der Meer, Ostelo, Jacobs, & van Schayck, 2004). Even if a smoker is able to stop smoking, nicotine addiction remains present for many years as shown by relapses in ex-smokers who try a single cigarette a few years after quitting and immediately relapse (Tønnesen et al., 2007). For smokers with COPD life can be complex in many ways and even though quitting smoking is an absolute necessity they find it overwhelming and extremely difficult to commit whole heartedly and let go of their “friend” (Jonsdóttir & Jonsdottir, 2007).

People with COPD do not necessarily relate the progress of the disease to tobacco smoking. They tend to doubt that the disease only emerges because of smoking, and believe it has multiple causes like that it runs in the family and/or is due to pollution at their work place (Halding, Heggdal & Wahl, 2011; Berger et al., 2011).
Self management and partnership

People with COPD tend to delay seeking medical help (Arne et al, 2007; Halding et al., 2011). However, whether they seek help early or late in the disease process it is important that health care professionals approach them in a manner which helps them to become more able to manage their chronic disease and improve their quality of life. The approach must be at a non-judgmental basis where individuals are met at the place they are situated in order for them to be able to accept and apply the intervention being used (Jóndsottir, 2013).

Self-management has become a popular term for management of chronic conditions (Lorig & Holman, 2003). Living with a chronic disease often demands daily self-management tasks like taking medicine by a plan, maintaining a special diet, exercising, observing symptoms and responding to changes in symptoms (Rosland & Piette, 2010). Self-management is to engage in activities which protect and promote health, monitoring and managing symptoms and managing the effects of illness on physical and mental function in cooperation with health care professionals and the community resources (Bycroft & Tracey, 2006). In modern health care systems more demands are gradually made on patients to actively take part in their daily treatment. Health care professionals support patients to be responsible for their own health and daily treatment (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002; Richard & Shea, 2011).

Predominant ideology about self-management states that it is “to teach and educate patients with the skills needed” to effectively manage their symptoms and condition (Barnett, 2009, pg 4). Prescriptivism seems to have sneaked into the ideology on self-management (Jónsdóttir, 2013) where authors say their most significant aim is to “change patients’ behavior” (Bourbeau, 2009, pg 8). It is assumed that the health care professional knows and decides what is in the patient’s best interest at the time (Jónsdóttir, 2013). Self-management programmes seem to be standardised and tailored to the health care professional rather than the individual patient (Lawn, McMillan & Pulvirenti, 2011). Thus,
the main thrust has become to manage the disease but not the personal experience to life with it (Jónsdóttir, 2013).

Many COPD patients are not attending self-management programs despite referral and/or fail to complete them for various reasons (Sohanpal, Seale & Taylor, 2012). An on-going multi-faceted approach is needed to manage the variety of symptoms and problems COPD inhabits. Luker & Chalmers (2010) studied patients aged 60-80 years old with moderate to severe stage of the disease along with their cares and showed that the patients were preoccupied with managing the strain that the disease “imposed on them” in daily life (p. 564). Despite having attended pulmonary rehabilitation they were unlikely to actively seek information and health promotion services and even seemed unaware of possible activities and ways to improve their health.
Summary
COPD is a growing disease, usually caused by smoking, of which symptoms gradually affects peoples’ daily life. Underdiagnosis is common and a greater identification of at-risk individuals is needed. However, individuals tend to underestimate or neglect the severity of their symptoms which often develop for many years. People with the disease often experience stigma and shame which can hinder them from seeking health care. The most difficult hindrance is the addiction to nicotine which is characterized as highly addictive by physiological, social and psychological factors. Self- management is the most common approach for management of the disease. Self-management programs seem standardized and people often fail to complete them. More research is needed to realize and understand the experience of COPD at its beginning stages in connection to addiction, shame, self-management and related issues.
Methodology

The purpose of this qualitative study is to describe and explain the experience of individuals with COPD and their families of the disease at its beginning stages for the purpose of gaining insight into the effects of the disease on daily life, the development and manifestation of symptoms and how people come to terms with the disease. An increased understanding of this experience may facilitate development of health care which is sensitive to the needs of these families. Interpretive phenomenology is used to reveal the meaning of being a human being in a particular situation and is therefore an appropriate method (Leonard, 1994; Benner, 1994). The research question is: How do individuals with COPD and their families experience the disease at its beginning stages?

Interpretive phenomenology

Interpretive phenomenology is rooted in the philosophical tradition of phenomenology (Leonard, 1994). A phenomenon is something which appears to human consciousness. That which appears is not only what is seen but also what is heard, thought or sensed in any way. A phenomenon can be other people, nature, pain or memories, for example. When something appears to human consciousness a certain experience, understanding and knowledge is obtained. The subject of phenomenology is to describe a phenomenon strategically as it appears (Dan Zahavi, 2008). As a subdivision of phenomenology, interpretive phenomenology is used not only to describe but also to interpret and understand human experience; what is it to be a person. To the person things have significance and value which is based on her/his culture, history, language and situations. These things are of concerns to the person and differ between persons. In asking what it means to be a person it is necessary to enter the person’s world and at the same time gain perspective on how the person knows the world. The world, in this sense, refers to meaningful sets of relationships, practices and the
language the person has by virtue of being born in the culture. The world shapes the person and the person shapes her/his world as nothing can be encountered independent of language, background, understanding and culture (Leonard, 1994).

A phenomenon must be understood in its context. Particular events must be understood in terms of history as well as the current situation as people’s lives are complex and in constant movement. Understanding makes a basis for interpretation of the world of people and events. For the purpose of understanding the researcher goes backwards and forwards and reflects on the text and the context of things in order to attain meaning (Benner, 1994). The goal is to uncover commonalities and differences to understand the world and what is of most concern to people. The five sources of commonalities, as articulated by Benner (1994) form the basis of data collection and analysis, are: 1) Situation – an understanding of how the person is situated currently and historically. 2) Embodiment – the person is embodied rather than having a body. The embodied self encompasses behavioral, perceptual and emotional responses. In a healthy body people take the unity of the embodied self for granted until it breaks such as in illness. 3) Temporality is the experience of lived time in both present, future and past, that is, how one projects oneself in lived experience of time or timelessness. 4) Concerns are what matters to the person in a particular situation; what is noticed and what has meaning. 5) Common meanings are taken-for-granted linguistic and cultural meanings (Benner, 1994; Leonard, 1994).

An understanding of human experience always includes interpretation by the one who describes it. The researcher’s background and personal experience, therefore, affects interpretation. The researcher has a pre-understanding of the research subject based on personal and cultural background and must recognize that before she/he starts the research process. The pre-understanding shapes the way the researcher sees things and the way things shape pre-understanding. This pre-understanding has been called the fore-structure of understanding and has
three aspects (Plager, 1994): 1) A *fore-having*: The person comes into a situation with a practical familiarity, that is, with background practices from his/her world. That approach makes interpretation possible. The environment, the researcher’s upbringing, education and experience has formed him/her as well as the participants and all have ideas about the research topic. 2) A *fore-sight*: Because of background the person has a point of view from which to build his/her interpretation upon. 3) A *fore-conception*: In relation to the background the person has some expectations of what might be anticipated in an interpretation.

*Author’s preunderstanding*

Fore-having: For the last five years I have met and cared for many patients with COPD both at my daily job at the pulmonary inpatient unit at Landspitali University Hospital and in participating in the research on people with COPD at beginning stages. It has caught my attention how far the disease has processed before people first seek medical advice and how often people do not seem to realize that they even have the disease. Frequently, they seem to deny its existence and it may not be until people are hospitalized at the acute pulmonary unit, presenting a life-threatening exacerbation, that they finally are diagnosed with the disease. For some reason they have not paid attention to the symptoms of the disease or sought medical advice earlier. In the intervention study my part was to contact participants and invite them to take part in the research as well as meeting them when they first came to the research center. Many questions awoke in that process and I noticed that those who came seemed to have made quite an effort to actually be able to come. Sometimes they were nervous and even defensive at first, especially those who were still smoking. I also noticed that many of them did not bring a family member with them and some of them had not even asked a family member to come despite my encouragement to do so. What especially caught my attention was noticing how many did not seem to
realize that they had the disease which made me think about how it would be possible to gain people’s attention earlier and how they could be approached in a helpful way.

Fore-sight: Based on my experience at my job and by reading literature I have a certain point of view. I believe health professionals must find ways to help people at the beginning stages of COPD to realize that they have a disease even though they seem to want to deny it. Nicotine addiction is very powerful and pulls people away from trying to quit smoking and from admitting the existence of the disease. Rather than accepting that people avoid being helped, I believe it is our obligation to develop health care where we non-judgmentally and respectfully are able to establish partnership with the people and work with them to delay or stop the progression of COPD.

Fore-conception: Much is written about the experience of advanced COPD but to my knowledge research on experience of the disease at its beginning stages has just newly started. It is my hope that with this study a new and a deeper understanding on people’s experience of the disease at the beginning stages and how it manifests in their lives, will be gained. I also hope that an understanding on what hinders these people from realizing the existence of the disease will be enhanced.

**Participants and setting**
The criteria for selecting participants in this research were individuals with COPD, stage II and III and family members who participated in the intervention study, *Partnership to enhance self-management of people with COPD and their families*. The participants who originally were recruited from eight primary health care centers in Reykjavik capital area and six private lung physicians’ offices at Læknasetrið, had by the time of this research finished the one year intervention. For participating in this research the individuals had to have been
accompanied by a family member to the original study. The individuals received an invitation letter to a focus group for data collection. In the letter they were also informed that a subsample of those invited to the focus groups would be invited to take part in a family interview (Appendix 1). All of the individuals who were accompanied by a family member in the original study and who finished the study were contacted for the focus groups (n=18). In all there were four focus groups with seven to ten people in each group (n=34). In two of the focus groups there were families who had been in the intervention group and in the other two focus groups there were families who had been in the control group.

After the focus group interviews had been conducted a subsample of families was chosen. Seeking maximum variation and demographic characteristics (Sandelowski, 1995), the inclusion criteria for the family interviews were that a) the family had been enthusiastic to share the experience in the focus group, b) the individual with COPD and the family member is of relatively young age (preferably < 60 years) since influences of the disease might play out stronger for younger persons and c) the families have diverse background, employment and social status.

The data collection for the focus groups took place in the same place as the original research, i.e. the Nursing Research Center at the University of Iceland. To meet at a place the participants know helps to create natural environment and it is important that participants are comfortable. The participants had already visited to the research center a few times before and during the interviews it was emphasized to create a comfortable environment and atmosphere (Bender 2012; Benner, 1994).

About three to five months after participating in the focus group individuals were invited to the family interviews. Everyone was willing to take part except two couples who were occupied or out of the country during the time period available. For the family interviews participants were able to choose, at their convenience, whether it took place at their own home or if they would come to
the research center. Six families chose their own home and two couples came to
the research center, making a total of sixteen participants, eight individuals with
COPD and eight family members.

Data collection
Data was collected in two phases. First there were four focus group interviews
and then eight family interviews.

Focus group interviews are a form of qualitative research that involves
organized discussion with a selected group of individuals who have something in
common (Bender, 2012). The purpose is to gain data on their views, experience
of the topic discussed and to obtain different perspectives about the topic. The
group usually consists of 4-12 people and in each research there are 3-6
interviews, each about one hour. The interviewer (moderator) plays a critical role
in the success of the interviews. She/he guides discussion according to a set of
questions or topics and must make sure to solicit input from all group members
and see to that the conversation is floating. A good knowledge on the topic is
necessary. A respectful atmosphere is promoted and she/he listens actively to the
participants narratives. An observer (assistant moderator) is usually present and
has the purpose to observe each session and notice unspoken expression (Bender,
2012). In this study the moderator was a clinical assistant professor, a member of
the research team and currently working at an out-patient clinic for people with
COPD. The author took part in all the focus groups as an observer, joined by
another observer as well.

Focus group interviews are likely to be efficient as the researcher obtains the
viewpoint of many people in a short time. It is based on interaction between
people in a group; people react on what is being said by others, thereby leading to
data that is less likely to be revealed in individual interviews. This quality is one
of the advantages of focus group interviews. Another advantage is that the people
in the group can share their mutual experience which can result to individuals in the group gaining a new perspective on their own situation. A concern is that some people are uncomfortable about expressing their views in front of a group and people who tend to dominate discussion can be a part of such a group. A tendency to agree with others in the group can also be of concern. Most of the concerns are related to the moderators’ knowledge and training and therefore making his/her approach critical as described earlier (Bender, 2012; Polit & Beck, 2012)

*Family interviews* provide a different window on the research topic than focus group interviews, as they usually offer more detailed data (Jónsdóttir, 2012). When focus groups are followed with family interviews a comparison on the individual response and responses from the focus group context can be made (Hollander, 2004). In this study data was collected with two researchers through eight approx. one hour-long family interviews which were audio-recorded and transcribed verbatim. The same two researchers took part in all the interviews, one as a main interviewer and the other as an observer. A master’s prepared nurse, who is a member of the research team and currently working at an outpatient clinic for people with COPD, was the main interviewer in some of the interviews and the author in the others. This nurse is experienced in working with individuals and families dealing with COPD and taking interviews based on interpretive phenomenology and was therefore of much support to author. A good familiarity of the subject and experience is considered important and the presence of two researchers can increase the quality of hearing what is said and what is left unsaid (Benner, 1994; Kvale & Brinkmann, 2009)

Since the family interviews followed the focus group interviews the questions were formed in the context of what had already been revealed and what the author and the research team considered critical to understand more precisely (Benner, 1994). Of most concern was to gain a deeper understanding on shame, the course of events as the disease manifested itself in the person’s life, being
diagnosed and what obstacles there were in the way of facing the existence of the disease. The author created a draft of questions for the family interviews and in cooperation with the research team a frame was formed (Appendix 2). Reviews and reflections from other researchers were helpful to uncover blind spots and find the most appropriate questions (Benner, 1994).

For both the focus groups and family interviews the main interviewer opened the interview with an introduction explaining the purpose of the conversation and how it would be conducted, how participants were chosen into the research and reminded them of the confidentiality of the researchers. Then the informed consent was signed (Appendix 3). The observer noticed the setting and non-verbal expression like facial expression and atmosphere. The observer could also chime in the conversation in order to ask further about subjects, extract commentary or run back over earlier parts when needed (Bender, 2012; Benner, 1994). The audio recording started after the introduction and participants were told how the findings would be used and published and that the audio recording would be deleted after the research. For the purpose of this research it was emphasized to set the interview up in as a naturalistic way as possible and create open atmosphere so the participants would feel free and unconstrained to express themselves (Benner, 1994; Jónsdóttir, 2012)

The interviews were formed as semi-structured in depth interviews (Kvale & Brinkmann, 2009). An emphasis was placed on phrasing questions in everyday conversational language so participants could respond spontaneously. The experience was examined from different perspectives and a focus was placed on the extraction of narratives or commentary from situations in the person’s life. When people structure their own narratives they are describing their immediate experiences and are less likely to use false generalities or ideology than if they are only answering questions giving facts or opinions (Benner, 1994; Kvale & Brinkmann, 2009).
The opening question, for both focus group and family interviews, was intended to bring out a description of the experience in the most open way possible: “What is of most concern to you about the pulmonary disease, what is now on your mind or matters the most to you?” This question affects and sets the tone for the whole interview and therefore it is important that the opening question should be appropriated (Fleming, Gaidys & Robb, 2003). Certain questions followed this opening question both to invite conversations about the issue of the study and to explore it as thoroughly as possible (Jónsdóttir, 2012). The questions formed a direction in the conversation without controlling it (Kvale & Brinkmann, 2009). Issues probed in the question frame were in connection to what was mostly of the participants concern at the present time, how they first came in to terms with the disease, how symptoms of the disease affected their daily life, what emotions they experienced related to the disease, if they experienced shame or guilt and how they talked about the disease with others. Additional issues in the family interviews were concerning what had proved most helpful in addressing the disease, what they thought would be most helpful for others in similar or same circumstances and if they would have done something differently if they could start all over again. Questions were also asked about family support, how people viewed themselves in the near future (3-5 years) and about the experience of quitting smoking. Questions were aimed both at patients and family members separately.

For the purpose of this study it was important to seek the meaning which participants put in their experience and to notice both spoken and unspoken expression. The researcher focused on being open-minded to what was expressed although it might sound new and unexpected (Kvale & Brinkmann, 2009; Benner, 1994). Sensitivity towards that which was being conveyed and allowing the participants to tell the story in their own way without interrupting the narrative was also of high importance. The question frame sometimes caused the conversation to go back to some issues already discussed which often gave a new
aspect on the topic. If needed, the interviewer asked for clarification on details of stories or asked questions to better understand and/or be sure to understand correctly what the participant’s meant (Benner, 1994). There were no follow up interviews but care was taken by the end of each interview to sum up its main content (Jónsdóttir, 2012; Benner, 1994). After each interview the researchers discussed their impressions, what they noticed, what was surprising and reflected on their focus for the next interview.

Data analysis

The author transcribed verbatim both the focus group interviews and family interviews. As interpretation and analysis of data started simultaneously, the data analysis started in the first focus group interview. Along with the transcribed interviews, observation notes and authors diaries all were treated as text analogues (Benner, 1994). When transcribing the interviews notice was taken of meaningful actions in the living conversation like expressed emotions, laughter, silence, and atmosphere and so on. Such actions may help to interpret meaning as the researcher goes beyond what is directly said to deeper interpretation on structures and relations of meaning (Kvale & Brinkmann, 2009).

The text was read and re-read and the recordings were listened to over and over again to correctly present the voice of the participants. To begin with, the text was read as a whole and then it was categorized and certain parts carefully inspected repeatedly until a meaningful whole without contradiction was developed. This was done by setting notes on the margins of each transcript which then were gathered and compared with each other in order to classify issues which reoccurred and were common in the data set. The meaning was interpreted by working out structures and relations of meanings not immediately apparent in the text (Kvale & Brinkmann, 2008; Green &Thorogood, 2004).
The approach which was taken in this study was thematic analysis. Commonalities and differences were revealed and issues and patterns analyzed. The interpretive process is circular; the researcher moves back and forth between parts and the whole of the text and between foreground and background and situations (Benner, 1994). This is an ongoing process of rewriting, which demands staying close to the text which the researcher immerses him-/herself into and then distancing him-/herself away from it again to see it in a new perspective and ask further questions. Still, it is not enough to go back and forth in the text. The researcher must also go back and forth in familiarizing him-/herself with the world of the participant, withdrawing him-/her and ask critical questions about the world of the participants. It is important to notice and write down the absence of something, e.g. what the participants are not and what is left unsaid (Benner, 1994). This is a circle of understanding, interpreting and criticizing.

Validity
A definition of validity in qualitative research is not always clear as the experience and knowledge of the researcher is always partly reflected in the data. Using language to describe experience and the researcher’s ability to elaborate it has its limits (Jónsdóttir, 2012). Several means can however be practiced to increase validity, mostly referred to the research’s credibility (Rolfe, 2006). When the researcher is able to present recognizable description which reflects the experience of the participant’s, credibility can be achieved. Data collection must be thorough, valuable and contain descriptions and different perspectives on the experience studied. The researcher must describe his experience, background and concept as has been done previously in this study (Plager, 1994; Rolfe, 2006; Benner, 1994).
Validity can be increased when data is analyzed by more than one researcher and by peer review. In this study themes were discussed with members of the research team to ensure logical flow from the findings and to invite alternate interpretations. When developing the first draft of themes all comments and keywords from the text were organized and the ones which supported each other were grouped together. After writing and re-writing the text along with reading and listening to the interviews, themes emerged. Those themes were introduced to the research team and it proved helpful to compare contrasts and to discuss the meaning of the data. Critical questions were raised to help the author to contextualize and see new perspectives. To have more than one researcher collecting data also increases validity. In the data collection there were always both an interviewer and one or two observers (Cutcliffe & McKenna, 1999; Kvale & Brinkmann, 2009).

The author emphasized to be honest, accurate and self-assertive as well as to respect participants, present their experience properly and to be committed to the text (Jónsdóttir, 2012). Summing up at the end of each interview and keeping a diary and field notes also served to enhance the validity of the study (Smith, 1999; Munhall, 2003).

**Ethnical issues**

Four main principle rules of ethics form the basis of ethics for health research. In this study these codes of ethics were kept (Kristinsson, 2012):

1) The principle of autonomy: Formal ethical approval was obtained from the National Bioethics committee (no. 09-035-V3) [Vísindasiðanefnd] (Appendix 4) and the Data Protection Authority [Persónuvernd] (Appendix 5). Participants voluntarily agreed to participate based on full and open information as they were given both written and oral information (Appendix2) before signing
informed consent (Appendix 3). Information included the purpose and nature of the study, researchers’ confidentiality and the right to decline or quit participation was made clear.

2) The principle of non-maleficence – “first do no harm”. Information was also given on possible consequences of participation. In qualitative interviews data collection can be personal and create mixed feelings for the participants. The interviewer must be conscious of participants’ difficult feelings which might occur in the dialogue and offer appropriate assistance if needed (Kristinsson, 2012). In the information letter participants were informed that if participation in the study raised difficult emotional issues psychological assistance would be available to them upon request. No one asked for this service. Transcribed interviews were only accessible to the author, the advisor and two other members of the research team. Caution was made to treat sensitive data with particular respect and in a way which could not lead to recognition of the person (Kvale & Brinkmann, 2009).

3) The principle of beneficence. This study can be of benefit both for individual participants and for the group of people dealing with COPD at beginning stage. Interpersonal relationships occur in the interviews which can be a rich experience for the participant, which may obtain new perspectives in his life or situation (Kvale & Brinkmann, 2009).

4) The principle of justice. Potential participants for this study, i.e. those who finished the intervention study and were accompanied by a family member, were throughout the research all treated in a comparable manner and in accordance with the inclusion criteria and the research plan (Kristinsson, 2012)
Results

Twenty one persons with COPD stage II-IV participated in this study, along with twelve spouses and one daughter. To simplify the text the word “patient” is used to indicate individuals who had COPD even though I do not consider them as typical patients. The group of patients consisted of seven men and fourteen women. They were 51-68 years old. The family members were 29-73 years old, eight men and five women. All patients had smoked but the majority had quit. A few family members smoked. The majority of the patients were at stages II and III (57% stage II and 29% stage III) of the disease but three patients were at stage IV (14%). Coincidentally, these three were all in the family interviews. Of eight patients in the family interviews, three were at stage II (38%), two at stage III (25%) and then three at stage IV (38%). Those who were in the advanced stages were particularly articulated about the time when the disease first manifested in their lives and could talk more openly than those at earlier stages about issues such as self-blame. Even though a concerted effort was made to get the family’s point of view the results are mainly from the patient’s perspective as both patients and family members mainly spoke within that frame of reference. The main themes, not mutually exclusive, that emerged from the data were:

“Self inflicted”, shameful disease
Enclosed in addiction
Living in parallel worlds – patients and family members
Getting to the end of the robe to realize the disease
Call for sympathy and hope
“Self-inflicted”, shameful disease

Participants believed the disease was self-inflicted. Shame was an underlying factor, or as one patient described it: “It’s just the way I see it, It’s just my own fault. If I hadn’t been stupid enough to smoke or had quit sooner I would have been much better…there’s no one [else] to blame. That is what I tell my kids; that this is all because of the smoking”. Even though patients had trouble with seeing the disease as a consequence of smoking they certainly felt they had brought it upon themselves “You just did this to yourself, whether or not it is because of the smoking”.

Participants experienced contempt from other people. They perceived that other people believed that their own smoking had gotten them into this situation. They were ashamed of themselves because of this: “See, you know you´re guilty...because COPD is always something that people consider as ‘ok, she smoked’”. It is like being the “dirty children of Eve”. Strikingly many participants denied feelings of guilt and shame when asked even though shame came strongly across in the conversations, by using different words or weaker expressions. Yet, in some family interviews a stronger expression was used especially by those who were actively working on realizing the implications of the disease. One lady described continuous shame and anxiety in her life: “Yes, I can say that shame comes over me all the time ...and I’m scared to death of this disease.” Later she said:“and then [when this comes over me] I feel like, oh, it’s all so dreadful and my own entire fault”. This same lady said that shame had hindered her in seeking the help she believed she needed: “Oh, that I sort of didn’t deserve it, I did this myself and why then should I let someone service me”. 
Enclosed in addiction

A major factor that makes it difficult to face the existence of COPD is the aspect of nicotine addiction though participants did not put it that way. Addiction was a strong thread through all the conversations. Commonly they described the pleasure from smoking and that they did not want to miss it: “it was just so good to smoke”. At the same time pleasure was described it was accompanied with expressions of regret. For most of them it was a great struggle to quit. They had to use multiple tactics and the risk of failing was always present: “I am constantly in a struggle... I deal with it like the alcoholics, I am not going to start smoking again”. The ambivalence which participants felt was reflected in their view that they would not have done things differently if they could start all over again. One lady said that if she had not gotten sick she would definitely have continued smoking: “the cigarette is number one”.

At the time when participants started smoking it was considered fashionable. Some felt bitter over how much effort they originally had to put in starting to smoke and now when they had to stop, they couldn’t. But now they were enclosed in the bondage of habit and addiction. From the time when smoking was considered an attractive quality the attitude in society has changed dramatically: “When I started smoking it was considered fashionable and not dangerous”. Often they had been defensive when someone, trying to be helpful, pointed out the importance of stopping smoking. One said she didn’t seek medical help because “I wasn’t going to let someone tell me to quit smoking”. Another couldn’t find any reason why she didn’t seek medical help earlier: “I don’t know why I didn’t go to the physician because of this [symptoms], just don’t know”.

Participants eagerly pointed out that there could be other reasons than smoking for the disease e.g., childhood whooping cough, dust and pollution. It seems like the addiction conceals participants’ thinking and takes predominance over their knowledge. A few participants had lost their parents because of COPD but still weren’t able to quit themselves at that time. One patient told a story
about her father who had COPD and was dying of it. He begged her to quit smoking but she could not consider his request: “He died from very advanced COPD and he asked me to stop smoking. And this often comes to my mind: ‘why did I not do it?’”. She could by no means figure out why she had not quit at that time: “Well no, I just, I just can’t find any reason for it, why I didn’t do it”. Looking back she felt this didn’t make any sense and the feeling of shame was nagging her.

Living in parallel worlds – patients and family members

The lung disease went more or less unrecognized in the daily life of the families. Family members did not know much about what the disease meant for the patients and the patients kept it to themselves: “I have this problem and I have to live with it”. Patients’ did not see a reason to talk about the disease to others: “This is just my private problem”. Therefore they tended to hide the disease both from themselves and others, even their closest family members: “This is a secret disease...you don’t want others to know that you have it...rather you struggle alone...I would never admit that I have the disease...I wouldn’t. Another one said: “I hesitate to say that I have COPD. Usually I say: I have asthma”.

Hiding the disease and being ashamed of oneself was frequently described in relation to having walks with others: “I don’t want other people to notice that I am out of breath when going up hills”. They even hid it from their closest family members as one lady described when she went downtown with her husband and pretended that she was window shopping when in fact she was catching her breath: “It didn´t even cross my mind to say ‘one moment, I can´t make it any further for now’, instead I just said ‘hey, look at those pipes in the window!’”. The husband didn´t have a clue at that time as to what was going on.
Needing to get to the “end of the rope” before realizing the disease

Participants described difficulties facing the existence of the disease despite warning signs along the way. It was not until they hit a wall and the symptoms of the disease had become so severe and obvious that they “woke up to a bad dream” and began to realize what COPD entailed. Stories of acute visits to the emergency room or waking up at the intensive care unit were common events which made patients realize what was going on. In conversation, especially in the focus groups, a tendency to diminish difficult issues and divert the discussion was noticed.

Over several years there had been various indications that something was going on as regarded the patients’ health, “but I wasn’t dwelling on it”. This something insidiously got worse but participants adjusted to it and even didn’t notice it in their daily lives; “It just happened so slowly, maybe I didn’t notice it”...“Gradually it just takes more time to do things”. They diminished their symptoms and did not see themselves as sick even though they described a lot of symptoms of the disease: “I wasn’t exactly sick, I was just breathless”. In their mind symptoms were not put in the context of a disease: “I knew there was something wrong with my lungs, but somehow I didn’t contextualize it with a disease like this”. These were symptoms like chronic cough, repeated lung infections and breathlessness. As long as participants could go to work they saw themselves as healthy and continued with their daily routine: “One just goes to work and does what one has to do”...“well yes, I had gotten lung infection and all, but I just got penicillin and continued my daily work”.

In most cases a long time passed until the participants were diagnosed and some even did not know they had the disease until they got the invitation to this study. “I didn’t know that it was COPD, still I knew there was something going on because I’d been using inhalers for about ten years”. They were disappointed and felt they should have gotten the diagnosis earlier: “My family doctor sent me
to this test [spirometry], which I maybe should have gone to like five years earlier”. They were stunned that they had not been told about it: “Why then didn’t he [the family physician] tell me about it...the name of it”. Some had gotten the wrong diagnose at first, so the journey could be long: “I mean it’s damn harsh if you have to be almost dead at the hospital to get diagnosed”. Some felt that the physicians did not understand what was going on: “one has asthma until one gets on their knees in front of them”.

Being diagnosed with the disease was a turning point in the lives of several people: “I believe for me that being diagnosed meant a great step forward physically...when I knew what it was I could start dealing with it, it wasn’t until then”. Others did not really take the diagnosis seriously at first. “I think I just sort of didn’t take it seriously” or “I just didn’t listen at all”. For some it took a long time to accept the disease and a few were still at odds with it: “I wasn’t at peace with it...It took me a long time to get it”. Most went the hard way and did not really take it seriously or accept it until they were hit badly by a bad infection or a full blown exacerbation: “[You] don’t want to accept it and you just keep on until you reach a dead lock”.

Call for sympathy and hope
A lack of understanding, both from patients and others in their closest circle, as well as society as a whole, was strongly emphasized both by patients and family members. All wanted information to be spread about what the disease inhabits and how it develops: “I feel like there is a lack of exactly describing what this is, how it will develop and how it will be...it’s like, no one has really heard a single thing about this”. Still there were a few who had sought information themselves and felt that the information was too intimidating “I got two booklets, then I started reading and I just got so shocked that I just closed it....it’s just like, this is so depressing”.

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The discourse in society about people with COPD was considered dissatisfactory both in terms of lack of real information and also because the stigmatization: “There is nothing at all [discourse about this], people in general don’t know anything about this and one hardly knows anything oneself”. The only common knowledge about COPD is that it is self-inflicted: “It is just a taboo because everyone says if you have this disease you must have smoked…and you deserve it because you smoked”. In addition to this attitude they feel like people think: “It served you right because you smoked” and if you cannot quit it’s just your own “gutlessness”. It seems that people close to participants did not realize how sick they were because “it can’t be seen on the outside” and “people just don’t figure this out or realize how serious this is”. When the disease becomes more apparent the approach may change to blaming them for not being able to get themselves out of the situation.

Being diagnosed late in the disease process was disappointing and consequently drained hope of getting better or succeeding the disease. To get this diagnosis was like a judgment on their life. There were instances where they were told that the disease was incurable and that there was nothing they could do to get better, or as one spouse phrased it: “[The physician told her] she was just stuck, if she continued to smoke she would get worse but she could in fact not regain anything at all”. This was experienced as a judgmental attitude: “Now you are in this ‘junk status’ and you’re just stuck there for the rest of your life”. This person had, however, been able to improve her health radically during this study and had a tone of disappointment in her voice when she said in regret: “I mean, why is this being told to people!”

Different from this judgmental and stigmatizing approach from health care professionals, participants – both patients and family members – called for information being given by professionals both about the reality of the situation and also about what could possibly be done to improve their condition even though the disease itself cannot be healed. They want to be given hope that
something can actually be done, “the positive path...the information needs to be available: what you can do to make the disease stop from the time of being diagnosed and that you are able to actually change some things”.
Discussion

This study is about the experience of individuals with COPD and their families of the disease at its beginning stages. The period before and when the disease was diagnosed was especially analyzed. The study gives an insight into patients’ feelings of shame and stigma. Their whole thinking, as well as other people’s thinking, was colored by the perception that COPD is self-inflicted. Patients were ashamed and tried to hide the disease even from their closest family members. In silence, they wrestled with strong addiction which seems to have predominated their awareness and actions. Patients had difficulties facing the existence of the disease and it took them a particularly long time to realize it despite various indications along the way. Some could not recall conversations of any kind about the disease despite having sought medical care and been prescribed pulmonary medications. Even though they had some symptoms of COPD they tended to minimize both the symptoms and their concerns regarding them as well as their health in general. The diagnosis became a turning point for several people. Both patients and family members were preoccupied with a lack of general understanding about the health problem of COPD and called for more understanding and sympathy from the people they interacted with, as well as, and even more strongly, people in society and the health care system.

Few studies on the experience of COPD at its beginning stages were located (Arne et al., 2007; Linquist & Hallberg e, 2010; Berger et al., 2011). The results of this study are in harmony to what has been revealed. Different from those studies, this study illuminates the long and difficult process it is for the individuals and their family members to realize the existence of the disease. In the literature it has been emphasized that COPD is underdiagnosed (Lindberg, Bjerg-Bäcklund, Rönmark, Larsson & Lundbäck, 2006; GOLD, 2013) but what it entails for the individuals involved has been of less attention. Shame was found in studies of people newly diagnosed with COPD (Arne et al., 2007) and was prevalent in this study as well. Participants even had difficulties putting their
experience in to words which, however, could clearly be inferred from their expressions. Shame was an apparent obstacle for seeking health care both in this study and in Arne’s et.al. (2007). Self-blame because of COPD is commonly associated with smoking (Plaufen, Wamboldt & Holm, 2012; Halding et al., 2011; Sheridan et al., 2011; Linqvest & Hallberg, 2010) and was repeatedly and strongly expressed through this study. Stigma is another phenomenon that dominates the experience of beginning stages of COPD (Berger et al., 2011). Halding et al. (2011) found that patients no longer felt like being full members of the “world of the healthy” after becoming diagnosed with this disease. They felt discredited because their diagnosis was judged by society as being smoking-related and self-inflicted. As in the current study, patients in Halding et al.’s (2011) study felt most contempt from others in their own social circle.

Patients in this study revealed a strong nicotine addiction even though they did not admit it or phrase the word “addiction”. Rather, they spoke of a habit which only demanded the willingness of the person to quit. A heavy and continued struggle with quitting smoking was described. To quit smoking is a vital issue for a people with COPD (GOLD, 2013), but seems more easily said than done, when smoking has become “a need of their ‘taken-for-granted-body’” (Gullick & Stainton, 2006, p. 8). This happens even in the context of overwhelming symptoms and life-threatening exacerbations of COPD such as in Jonsdottir & Jonsdottir’s (2007) study who described the experience of women with COPD who repeatedly relapsed to smoking as “being caught in a spider web”. Some participants continued to smoke in order to reduce negative feelings and anxiety and portrayed the cigarette as their “friend”; an expression which has been described previously (Lindqvist & Hallberg, 2010; Jonsdottir & Jonsdottir, 2007). All of these expressions of nicotine addiction point to the intense ambivalence there exists between the pleasure and the need to smoke and the recognition that it would be best for the patientsto quit (Gullick & Station, 2006; Jonsdottir & Jonsdottir, 2007).
Much is to be learned about how health care systems should address addiction to nicotine. Addiction to nicotine is a chronic disease similar to heroine (U.S. Department of Health and Human Services, 2010), although it has been suggested that the health care system prioritizes these two addictions quite differently (Gullick & Stainton, 2006). The first step in addressing nicotine addiction is to realize that it does exist (Tønnesen et al., 2007). Patients in this study did not recognize their own addiction nor did they indicate that they had access to appropriate support. That indicates that much work is ahead for health care professionals when addressing nicotine addiction at the beginning stages of COPD.

Patients find it difficult admitting that COPD exists “just” because of their smoking (Bailey, Montgomery & Boyles, 2009). In this study, participants were eager to uncover additional reasons. To cling to those other reasons has been described as a way to enhance positive emotions by committing to memories from former job-related efforts and displacing self-blame (Halding et al., 2011). Furthermore, failure to overcome the body’s addiction to smoking could lead to denial of the relationship between the need to smoke and progressive breathlessness (Gullick & Stainton, 2006). Along those lines, the patients tended to conceal their disease from others around them. Strategies of secrecy, such as avoiding telling people about the disease and hiding physical impairment has been described previously. This game of hiding might, however, hinder people with COPD enjoying social support as well as delaying seeking medical treatment (Halding et al., 2011; Arne et al., 2011).

Little is known about patients with COPD at its beginning stages and participants in this study, both patients and family members, called for increased understanding and sympathy towards them. COPD patients have been described as a “forgotten” group of patients (Pols, 2013). A lack of empathy and support from society to manage this chronic disease has also been described (Halding et al., 2011; Cooke & Thackray, 2012). Patients have stated that they were exposed
to stigmatizing attitudes, leading to insufficient attention both from society in general and from healthcare professionals. They have also expressed a lack of understanding and sympathy and experienced negative attitudes, especially if they had not managed to stop smoking (Lindqvist & Hallberg, 2010). This harmonizes with the experience of this study. Patients’ experienced judgmental attitudes and family members approved to that.

In order to seek advice at the onset of the COPD patients need to know what symptoms might indicate the disease. In this study, patients often did not see themselves as sick and tended to diminish their symptoms. Expressions and descriptions of their symptoms were sometimes difficult to extract and despite breathlessness, chronic cough and lung infections these symptoms were not put in context of a disease. Symptoms not being recognized by the patients’ as sign of disease has been described both at the beginning stage (Arne et al., 2007) and at advanced stages (Pols, 2013, Bellamy & Smith, 2007). This, along with other issues, can lead to a prolonged diagnostic process. In this study, it was essential to most patients to get a diagnosis in order to be able to do something about their health. To get a clear diagnosis has also been described as crucial if patients are to do something about their situation (Arne et al., 2007). It is essential to diagnose COPD as early as possible before it has developed to the point where airflow limitation leads to a stage where exacerbation starts to become frequent and quality of life is reduced (Benediktsdóttir et al., 2007; Gulsvik et al., 2006). Early intervention could result in important reduction in mortality, morbidity and health care expenditures related to the disease (Hill et al., 2010; Bellamy & Smith, 2007). When considering that the burden of the disease is predicted to grow in coming decades (GOLD, 2013; Benediktsdóttir et al., 2007) it must be a goal to reach patients earlier in the process to delay the progression of the disease or even bring it to a halt.

In this study, and others of similar nature, are examples of patients seeking advice for symptoms like breathlessness but not getting a clear diagnosis or being
warned of the possibilities of developing a serious disease (Arne et al., 2007). There were stories of patients who went in and out of health care centers where they got acute symptom management, such as antibiotics and inhalers which reduce symptoms for some time only to come again and receive another “band-aid” without the root of the “wound” being addressed. Finally those “band-aids” stopped working and real exacerbations kicked in and the patients ended up being so ill they were hospitalized even to the intensive care.

Much is to be gained by helping people to realize the disease earlier in the process, before they “hit the wall”. A new health care service with the aim of forming partnership with people at beginning stages of the disease is suggested in order to delay the process of the disease (Jónsdóttir et al., 2013). Health care workers must realize the shame and the stigma that patients with COPD experience and make them selves available to act supportively. Patients are wrapped in shame and addiction, consciously or unconsciously, and health advice on smoking might make them act defensively as the feel they are being societally moralized (Halding et al., 2011). To respect peoples’ own personal stories (Bailey et al., 2009) and be sensitive when addressing smoking cessation in a helpful, non-judgmental way, is of importance. Health care workers tend to misinterpret patients’ shame and failure to quit smoking as a lack of motivation to change (Halding et al., 2011). Nicotine addiction needs to be recognized and treated as such (U.S. Department of Health and Human Services, 2010). Repeated smoking cessation along with social support must be available as patients are partners in decision-making (Halding et al., 2011). The attitude that smoking is just a behavioral choice of the patient needs to change in order for health care to be more helpful towards those patients (Blöndal, 2007). Negative emotions and shame can be a burden in the daily life of patients (Halding et al., 2011). To recognize that nicotine addiction is a chronic disease (Tønnensen et al., 2007; Jónsdóttir et al., 2009) might be helpful when addressing smoking and shame.
In the view that patients have difficulties facing the existence of the disease, and dealing with complicated issues like self-blame and addiction, there is a need for a firm follow-up following diagnosis. In this study participants described the need for and security of having reliable and timely access to a physician or a health care service. Patients need to be informed about the disease and what it entails. This information needs to be given step by step and on a form and at a speed which is acceptable for the patient. In this study those who brought a family member along clearly recommended for others to do so and described a great relief when they stopped hiding the disease from each other. Families must be considered clients of the health care system and invited along with patients as soon as the patients are ready for that.
Conclusion

This study shows that addiction and self-blame are predominant in the lives of people with COPD and their families at the beginning stages of the disease. The process of realizing the existence of COPD is a long and tedious one in which people tend to delay to seek medical help and hide the disease from others. Early diagnosis is important and patients need a maintained support in continuance with being diagnosed to be able to accept its existence, to manage it and deal with the challenge of addiction and shame. This might delay the progress of the disease which is a win-win development for patients, their families and the health care system.
References


Appendices
Appendix 1: Kynningar bréf [information letter] and þokarunnsunslýsingar [background informations]

Framhald rannsóknarinnar Eflying heilbrigóis og sjálfsumönnunar hjá fólti með langvinna lungmateppu og fjölskyldum þeirra

Ágæti viðtækandi

Fyrir nokkrar síðan lauk þátttöku þirri og áðurandana þins í rannsókninni Eflying heilbrigóis og sjálfsumönnunar hjá fólti með langvinna lungmateppu og fjölskyldum þeirra. Tilgangur rannsóknarinnar var að meta árangur fræðslu- og stöðningsmæðer fyrir fólk með langvinnu lungmateppu og fjölskyldur þeirra með áherslu á að hægja á framgangi sjúkdomsins og bæta lífsgerði.

Rannsakendur telja mikilvægt að rannsaka frekar utriði er líta að því að takast á við langvinna lungmateppu og lverning heilbrigóisþjónustun getur betur komið til móts við einstaklinga sem hafa sjúkdominn og fjölskyldur þeirra.

Þess er faríð á leið við þig að þú og áðurandandi þinni takið þátt í einum rýniþöpi sem haldinn verður í Rannsóknarsetri hjúkrunarþrúnnsókn (sama stöð og upphaflega rannsóknin) og þau ræðið í hopi 6-8 annarra einstaklinga í líðstæðum sporum um hvað kemur að gagni varðandi það að takast á við og lifa með langvinni lungmateppu. Viðtælið mun taka 1 til 2 klst.

Farið verður fram á það við nokkrar einstaklinga að taka auk þess þáttt á einu klukkustundarlönungi fjólskylduvíðaliti. Sem fyrir hestar þú fullan rætt á að hafna þátttöku án eftirnalda.

Nokkrum dögum frá útsendingu þessa bréfs verður hringt í þig og þér ásamt áðurandanda boðið í rýniþopiviðalit.

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Styrktaraðilar: Visindasjóður Landspitalans og Félag íslenskra hjúkrunarfræðinga.

Ávinnungur
Þess er vann að niðurstöðurnar varpi nýju ljósi á gagnsemi meðferða sem sætlað er að styrikja getu þolks með langvinna hunganætti og fjölskyldnà þeirra til að takast á við sjúkdominn á sem árangursrikastan hatt. Jafnframt því er þess vann að niðurstöðurnar gefi vísbendingar um hvernig heilbrigðisstafsmenn geta eftí heilbrigðisþjónustu fyrir þennan stækkandi hóp skjólstæðinga.

Nafnleyn og trúnaðir er hettíð
Heitið er nafnleyn og ekki verður hægt að rekja neinar upplýsingar til þátttakenda. Gögnin verða í vörslu rannsakenda þar til að lokinni úrvinnslu og eytt að henni lokinni. Niðurstöður rannsóknarinnar verða birtar í innlandum og erlendum tímarsgrænmum og um þor flutt erindi fyrrir heilbrigðisstafsfolk og almennung.
Þátttaka í rannsókninu hefur overulega áhættu í för með sér. Þér ber engin skylda til að taka þátt í þessari visindaramsókn. Þú getur hætt þátttöku hvenær sem er án eftirmála og þá mun ekki hafa áhrrí að þá heilbrigðisþjónustu sem þú og þin fjölskylda kann að fá í framtíðinni.
Rannsóknin hefur hlutið samþykki Visindasíðanefndar og Persónuverndar. Þátttakendur greiða engan kostnað af þátttöku í rannsókninu og fá ekki greitt fyrrir þátttöku í henni.
Guðrún Hlin Bragadóttir hjúkrunarfræðingur og meistaranesi í hjúkrunarfræðideild Húskóla Íslands mun útskýra fyrrir þér rannsóknina í gegnum síma og við komni í rannsóknarsetrið og eins er hægt að hafa samband við hana í síma 894-2362, netfang ghb7@hi.is og Helgu Jónsdóttur, professor við hjúkrunarfræðideild Húskóla Íslands sem er úbyrgðarmaður rannsóknarinnar í síma 525-4990, netfang: helgaj@hi.is

Með fyrrirfram þakkæti,

Reykjavík 1. júni 2012

Helga Jónsdóttir, hjúkrunarfræðingur, prófessor

Guðrún Hlin Bragadóttir, hjúkrunarfræðingur

Ef þíði hafði spurningar um rétt ykkur sem þátttakendur í þessari visindaramsókn eða viljist hætt þátttöku í rannsóknini getið þíði snúið ykkur til Visindasíðanefndar, Tryggvagötu 17 s/ví: 551-7100, fax: 551-1444.
Efling heilbrigðis og sjálfsömunnunar hjá fólki með langvinna lungnateppu og fjölskyldum þeirra

Fjölskylduviðtöl

Október - desember 2012

Rannsóknarspurningar

1. Hver er reyndla einstaklinga með byrjandi langvinna lungnateppu og fjölskyldna þeirra af sjúkdómmum?
2. Hver er reyndla fjölskyldna af fjölskyldum í samráði í sjálfsömunnar með fyrir einstaklinga með langvinna lungnateppu og fjölskyldur þeirra?

Viðtal

Kynna sig og tilgang samræða, hvers vegna þáttakendur voru valdir, segja að upptökk verði eytt og niðurstöður birtar á visindaráðstefnum, meistaraverkefnir og timaritsgreinum, taka saman meginatriði í lokin.

1. Hvað liggur ykkur á hjarta núna varðandi lungnasjúkdóminn, hver eru megin áhýggjufnir? Hvað skiptir ykkur mestu máli?
2. Hvergig áttu ykkur á tilvist lungnateppunnar, hvaða visbendingar voru fyrir hendi, og hvaða áhrif hafði það á ykkur?
3. Hvað hjálpaði ykkur mest að takast á við sjúkdóminn?
   a. Hvað haldið þið að myndi hjálpa fólki í ykkar stöðu mest?
   b. Ef þú værir að byrja að takast á við sjúkdóminn núna, myndir þú gera eittvænu öðruvisi en þú gerðir?
4. Hvaða tilfinningar gera vart við sig þegar þið hugsið um lungnateppuna?
5. Hafði þið fundið fyrir skömm eða sektarkennnd vegna lungnasjúkdómsins?
a. Fólk hefur stundum lýst sektarkennd vegna reykinganna eða vegna sjúkdómsins. Finnst ykkur það eiga við ykkur á einhvern hátt?

6. Hvernig birtast áhrif lungnateppunnar í daglegu lífi ykkar og fjölskyldunnar?

7. Saknið þið stuðnings frá fjölskyldu eða vinum eða upplifðið þið að stuðningur þeirra hafi skipt sköpum?

8. Hvernig sérðu heilsu þína eftir 3 ár/5 ár?

9. Hvernig hefur þér gengið að hætta að reykja? Er eithrvað í sambandi við reykningar eða hvernig þér hefur gengið í tengslum við þær sem þú vilt deila og gæti jafnvel hjálpað öðrum í sömu sporum?

**Reynsla af samráði í rannsókninni**

1. Hvaða er eftirminnilegast varðandi þátttöku ykkar í rannsókninni?

2. Hverju breytti þátttaka ykkar í rannsókninni fyrir ykkur? Og eða hafði þátttakan áhrif á líf ykkar á einhvern hátt?

3. Voru einhverjir vendipunktar varðandi lungnateppuna í tengslum við þátttöku í rannsókninni?

4. Hvernig hefur hugsun ykkar um lungnateppuna breyst eftir að hafa tekið þátt í henni?

5. Hafa samskipi ykkar tengd lungnateppunni breyst í kjölfar þátttöku í rannsókninni?

6. Fannst ykkur skipa máli að koma saman í rannsóknina?

SAMANTEKT
Appendix 3: Innpýst samþykki [Informed consent]

Upplýst samþykki skriflegt

Framhald rannsóknarinnar Efting heilbrigóls og sjálfsamönnunar hjá fólki með langvinna lungnateppu og fjölskyldum þeirra

Ég staðfesti hér með undirskrift minni að ég hef lesið upplýsingarnar um rannsóknina sem mér voru afhentar og hef fengið tekið af því að spyrja rannsækendur spurninga um rannsóknina og fengið fullmeðgandi svör og útskyrningar aatriónum sem mér voru óljós.

Ég hef af fúsum og frjálsun vilja ákvæðið að taka þátt í rannsókninni. Mér er ljóst að þó ég hef skriðað undir þessu samstarfsyfirlýsingu get ég stóðvað þátttöku mina hvenær sem er á útskyrninga og án áhrif á þá heilbrigóslýsingum sem ég á rétt á íframfinnini.

Dagsetning

Nafn þátttakanda: Einstaklingur með langvinna lungnateppu

Nafn þátttakanda: Aðstandandi

Undirritaður, starfsaður rannsóknarinnar, staðfestir hér með að hafa veitt upplýsingar um eðli og tilgang rannsóknarinnar, í samræmi við lög og reglur um visindaramsóknir.

Nafn rannsakanda

Upplyst samþykkt okkar fyrir þátttöku er í trú í og munum rannsækendur holda eftir dóru einstaklingu og þátttakendur inn.

Ef þú hefð spurningar um rétt stókar sem þátttakendur í þessari visindaramsókn eða viðstöð herra þátttöku í rannsókninni getið þú smáð yktur til Visindastöðavéitar, Tryggvagróðu 17 Simi: 331-7100, fax: 331-1444.
Appendix 4: Leyfi frá visindasiðanefnd [Formal ethical approval]

A fundi sinnum 03.04.2012 ljúllaði Visindasiðanefnd um umsókn þína dags. 26.03.2012, vegna viðbótar nr. 3 við ofangreindra rannsóknarættun.

Í breiðum kemur m.a. eftirfarandi fram: "Óskað er viðbótarleyfis varðandi rannsóknina Eflling heilbrigðis- og sjálfsamþönnunar hjá einstaklingum með langvinna lungnateppu og fjölskyldum þeirra.

Rannsókninni lýkur á næstu vikum. Úrvinsla er hafni á upphafsgögnun rannsóknarinnar en tilgangur hennar er að prófa árangur tiltekinnar meðferðar hjá einstaklingum og fjölskyldum sem glíma við langvinna lungnateppu (LLT) á stíg 1 og III. Í ljós hefur komið að einungis lítill hluti einstaklinga með LLT eða af þeim 119 sem þátt tóku höfuð fjölskyldumeðlun með sér. Þetta var lýsirði og veikur uppframleggar og kliniskar spurningar um hægri hluti neið fið eða glíma við byrjandi lungnateppu í að taka þátt í rannsókninni. Til að varpa ljósi á hvernig hægt er að nállest einstaklinga og fjölskyldur með byrjandi LLT og veita þeim meðferð sem geti hærð eða hægt á framgangi LLT er mikilvægt að afslá þekkingar um hægt gagnanum þessum 36 fjölskyldum sem þátt tóku. Langtímamarkmið rannsakenda var og er að þros heilbrigðisþjónustu bygði á niðursetum þessarar og fleiri rannsókna sem nær til fjölskylduna sem glíma við byrjandi LLT. Umin hefur verið rannsóknarættun um framhaldsrannsókna, sem send hefur verið til Visindasjóðs Landspítala og einung Félags isolenskra hjóknarafhæringa, þar sem um meðferðarhæringu er að ræða hafa rannsakendur haldið skrá yfir nöfni altra þátttakenda. Þannig er greiður aðgangur að þeim þátttakendum sem óskað er eftir til þátttöku í þessari framhaldsrannsókna. Meðfylgjandi er rannsóknarættun þessi drögum að kynnningarsvið og upplýstu samþykki. I rannsóknarættuninni koma fram ívar rannsóknarspurningar:

1. What is the experience of families participating in a partnership-based family-centered self-management program for people with COPD?
2. What kind of health service would families participating in a partnership-based family-centered self-management program for people with COPD recommend for families (indivduals and family members) living with COPD at the beginning stage of the disease?

Þessar spurningar liggja til grundvallar bedi í rýnihópavíðlendum og fjölskylduvíðlendum. Þeim verður fylgt eftir í viðtöllum með þessum að þátttakendur lýsi því hvað þeir tóka mikilvægt fyrir sig og hvernú þá hleva þeirra, hví þeim á óvart og að bili þá að hugging til baka nokkur ár aftur í tímann og veita fyrir sér hvað hefur verið gagnlegt fyrir þau þegar einkenni sjúkóm til gerðu vart við sig. Að lokum verður áhersla á hvað þau telja erflúst að taka á við varðandi langvinna lungnateppu. Gert er ráð fyrir að fjölskylduvíðlólin veití dýpri rannsóknargögn en þau sem rýnihóparinn gefa tilfini til."
I bréfinu kemur fram að sent hefur verið leyfisbeidni til Persónuverndar vegna þessarar framhaldsrannsóknar til að nota greiningarlykil sem hefur að geypna upplýsingar um þá þátttakendur sem höfdu fjölskyldumeðlim með sér í rannsóknina í því skyni að hafr samhanda við einstaklinginn með langvina lungnateppu og bjöða honum/henni þátttöku.

Víslindasislæfðin hefur farið yfir bréf þitt og gerir ekki athugasemdir við tilgreindar breytingar. Viðbót nr. 3 ásamt fylgigögnnum við ofangreinda rannsóku, er endanlega sambykkð af Víslindasislæfðin.

Áréttað er að ábyrgðarmannir ber að látu stofnunir, sem áður hafr veitti leyfi vegna framkvæmdar rannsóknarinnar, vita af ofangreindri breytingu á rannsóknaráætluninni.

Með kveðju,

[Signature]

dr. med. Björn Rúnar Lóðvíksson, læknir, formúþur
Appendix 5: Leyfi frá persónuvernd [Data Protection Authority approval]