



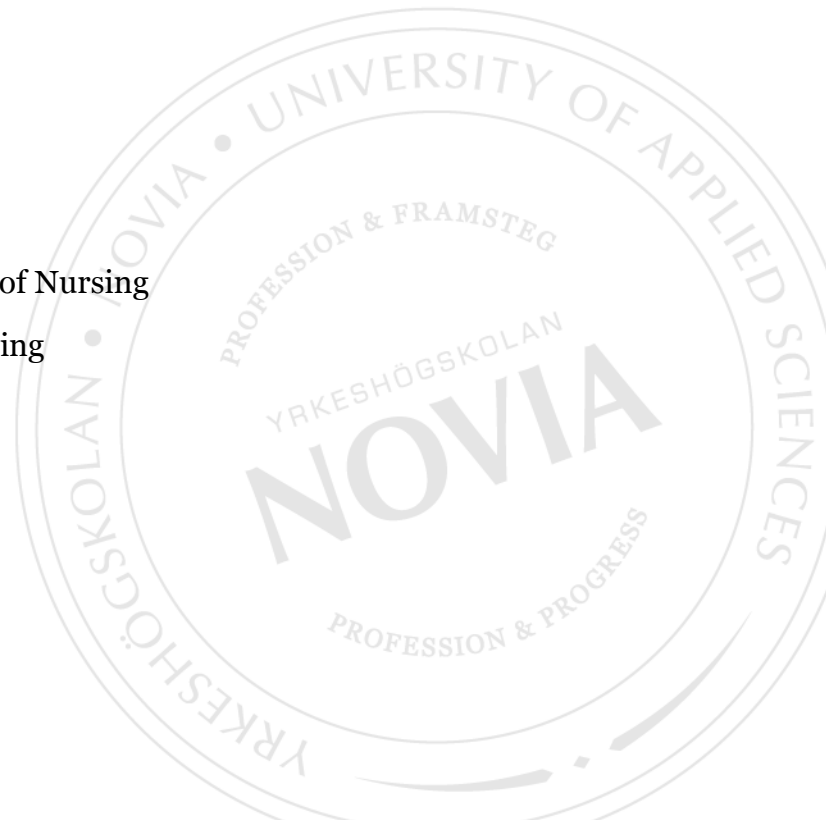
# **The experience of living with Sick Building Syndrome**

Jessica Sundin

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## **BACHELOR'S THESIS**

Author: Jessica Sundin

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Supervisors: Maj-Helen Nyback

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### Summary

This study aims to describe how Sick Building Syndrome can affect people. The study has its basis in in-depth interviews with two individuals. The study uses descriptive phenomenology to describe the effect Sick Building Syndrome has had on the participants' life and how Sick Building Syndrome has affected their quality of life. The study also aims at describing how these individuals perceived others' response to their symptoms and what their expectations were of health care professionals and employers and whether they felt that their expectations were met.

This study is part of the TEMA project which is a longitudinal research project between the area of Västerbotten in Sweden and Österbotten in Finland. TEMA is a multidisciplinary project involving not only academia but also other areas such as social and health sectors in both countries and professions concerned with technical aspects of building, such as engineers, architects, and construction builders. The TEMA project aims at creating a better understanding of building-related health problems among the general public, employees and employers, making sure that those suffering feel that their symptoms are taken seriously, that adequate and timely care is given and accurate changes are made. TEMA intends to coordinate current efforts in both countries so that best praxis is shared in both languages.

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Language:	English	Key words:	Sick Building Syndrome, Quality of life
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## 1. Introduction

People in the Western world spend more and more time indoors. We focus our efforts when building houses and buildings on energy efficiency and comfort. Our buildings are expected to have cooling and heating systems and be constructed as tight as possible to prevent loss of energy. In some cases we create windows that do not even open. We also use more chemicals both in constructing our buildings but also in keeping them clean (Heimlich, 2007, p. 1).

Since the 1970s, health care providers have noticed an increase in patients seeking help for allergy-like symptoms whose source could in the beginning not be specified. These symptoms were anything from irritation of the mucous membranes, eye and nose irritation, skin problems to fatigue, headaches, nausea and lethargy. Overtime we have learned that patients are experiencing these symptoms when they are spending time in a particular building and the symptoms tend to go away when they remove themselves from this area. The conclusion has been that the source of their symptoms is a particular building, thus the name Sick Building Syndrome (Norbäck, 2009, p. 55).

Sick Building Syndrome (SBS) is the common name for buildings that have flaws in their construction, mainly in their heating, ventilation, and air conditioning, or contaminants such as mold, dangerous construction material or chemical contaminants both from indoor and outdoor sources, causing health issues among people living or working in these buildings. Mostly SBS is caused by poor indoor air quality. Often problems occur when a building is improperly managed and maintained or if there are flaws in the design or reconstruction of a building or area in a building (Lyles et al. 1991, p. 67)

The connection between the building and the symptoms experienced is not always clear, making it difficult to diagnose. The problem is also that not all those who are exposed will have any symptoms or their symptoms will differ from each other, making it difficult to pinpoint the relationship between their symptom and the building they spend a large amount of time in. Also some areas in a building may be more prone to cause symptoms than other areas which makes it hard to identify. Common symptoms are irritation of the eyes, nose and throat, overall health decrease, skin problems, hypersensitivity reactions that are nonspecific in nature

but also odor and taste sensations. Acute headache, difficulty concentrating and fatigue are also common symptoms (Norbäck, 2009, pp. 55-58). Another problem is that there are currently no general guidelines for how to measure indoor air quality and determine the different pollutants in the air and their effect on different individuals. No generally accepted practices have been found, making research measurements difficult to interpret (Glas, 2010, p. 19).

Many of these symptoms may be confused with other causes such as allergies that can be contracted from other sources, other illnesses, and discomfort at one's workplace, job-related stress or other psychosocial factors. One of the keys to diagnosing SBS is that the individual's acute symptoms vanish or decrease when they leave the building. However, there is no clear origin of the health discomfort. Unfortunately, in some cases, even though the discomfort decreases when the individual is no longer exposed, some of the effects may linger and cause long term effects on the individual's health and ability to work. Another identifier of SBS is when several people experience similar symptoms within a close time period (Glas et al. 2008, pp. 1297-1303).

This study is requested by the Botnia Atlantica project and is called TEMA. TEMA is a project between the Västerbotten region in Sweden and the Österbotten region in Finland. The purpose of TEMA is to better understand the cause and symptoms of SBS and coordinate the efforts between different actors such as the health and social sectors, construction engineers, architects and builders in order to better support those affected by SBS. TEMA will be further described in the theoretical background chapter.

## **2. The Aim of the Study and Definition of Problem**

The aim of this study is to describe the lived experience when affected by SBS. This is a study based on the subjective experience of two individuals. The study will emphasize how these individuals experienced the disease, how they were met by family, co-workers, employers and whether they felt that their symptoms were taken seriously. The study also looks at the outcome and how the disease has affected their lives today.

The problem definitions are:

What is it like to live with SBS?

How does the disease affect the participant's quality of life?

How do the participants feel that they have been met by others such as family and friends but also health care professionals and employers?

I have performed in-depth interviews with two individuals, giving them the opportunity to tell their story. In my study I am using a descriptive phenomenological approach to describe the subjective lived experience of the participants.

Due to the limited amount of interviewees this study cannot by any means claim to make any type of generalizations on how people generally may be treated or feel when they experience symptoms of SBS. This study is also made in Finland where such things as weather conditions, building materials, ventilation/insulation may be different than in other parts of the world and therefore this study is exclusive for Finland and other Nordic countries with similar building construction and weather conditions.

### **3. Theoretical Background**

In the theoretical background I will explain the background of the study but also what theoretical framework I have used in my study. I will also briefly mention what previous literature I have used.

#### **3.1 The TEMA Project**

Due to lack of productivity and performance and due to short term and long term sick-leave, SBS costs the society tremendous amounts every year. Many nations are now putting more efforts into understanding and preventing SBS. According to Glas, only in the U.S. the cost of SBS due to sick-leave, lack of productivity and cost to health care is estimated to be between

4-70 billion dollars per year. Also in Sweden costs due to SBS are estimated at several billion SEK/year (Glas, 2010, p. 14). This paper is one part of a project called TEMA that is partly funded by the European Union.

TEMA is a longitudinal research project between the areas of Västerbotten in Sweden and Österbotten in Finland. TEMA is a multidisciplinary project involving not only the health and social sectors but also professions occupied with technical aspects of building, such as builders, architects and engineers. TEMA seeks to also involve governmental actors, both in Finland and Sweden that deal with health, environment and occupational wellbeing.

The purpose of the project is to exchange ideas and experiences and coordinate the resources at hand but also to inform the public about building-related diseases and how to avoid them. Through the collaboration between different professions TEMA seeks to understand the cause of disease and symptoms that negatively affect an individual's health. Up to this point the different actors such as engineers, construction workers, architects and occupational health professionals etc. have not communicated with each other towards a common goal. TEMA seeks to profoundly understand how SBS affects the life situation of those suffering from SBS but also to use chemical methods that have been developed to test individuals for sensitivity to substances in a building. By understanding SBS's cause and effect and its emotional impact on patients and its actual physical effects, TEMA aims at developing a comprehensive guide for all those professions that deal with people affected by SBS. Up until this point there has not been such a guide, with the result that patients often feel that their symptoms and illness are not taken seriously. Sometimes the symptom an individual is experiencing is seen as psychosomatic. Due to the lack of knowledge among different professional groups, patients are often not given the right care and support.

The intention of the project is thus to create long term sustainable development which will ultimately lead to wellbeing and growth in the regions that are affected by the TEMA project. Building-related illness costs the society too much each year due to long term sick-leave, health care, sanitation of affected buildings, early retirement, decrease of productivity etc. (TEMA project plan, 2011, pp. 2-13).

This study is part of the TEMA project. The study aims at focusing on the lived experiences of individuals that have been affected by Sick Building Syndrome.



## 3.2 Theoretical Framework

The theories I have chosen to apply in my study are Eriksson's theory on suffering (1994, p. 23, p. 82) and Bäckman's theory about environment and health (1991, pp. 13-14, pp. 25-27).

According to Katie Eriksson, suffering can be physical, that someone is in physical pain, but one can also suffer without pain. This type of suffering is often related to the feeling of not being seen and that one's problems are not taken seriously. According to Eriksson the human dignity lies in one's credibility. If others question your credibility they question you as a person which creates suffering (1994, p. 23). Suffering in itself is a violation of human dignity; if you take away someone's credibility and their dignity you cause suffering (1994, p. 42).

Health care institutions are created to help, support and if possible take away or at least alleviate suffering. However, it seems that this is only the case with tangible and known diseases. Unfortunately, if the patient shows symptoms of something that cannot be diagnosed the patient is often not taken seriously and the cause is said to be psychosomatic. The patient may feel that their symptoms are not real and their credibility takes a hit, creating unnecessary suffering. Katie Eriksson calls this suffering in *Caring and Health Care* (2006, p. 75). This type of suffering causes guilt, shame and degradation in the patient (1994, p. 84).

If a patient who approaches health care feels that they and their health problems are being questioned, Eriksson argues that this is indeed a questioning of the person themselves and their entire being. The experience of not being believed and not being accountable is the same as questioning one's own identity and importance, which creates incredible suffering (1994, p. 44).

Patients can experience suffering in health care due to the actual care they receive but also by not receiving adequate care. Eriksson has found that patients that experience suffering due to health care have the following in common (2006, pp. 79-85):

1. Violation of the patient's dignity
2. Condemnation and punishment
3. Assertion of power

#### 4. Omitted caring or non-caring

Suffering can, however, be the trigger to change in a person. This is the idea that out of something bad comes something good. Change does not necessarily have to be that something better happens but it can also simply be just coming to terms and accepting one's destiny (Eriksson, 1994, p. 48).

According to Frankl there are several different stages of transformation when one suffers. The stage of creation is the trigger to action, the stage of experience is the emotional trigger, or hope, love and positive outlook, and the stage of adjustment is your change of attitude and coming to terms with the past and the new situation. Through these stages one can accept and the suffering is no longer suffocating the individual. With support and care from others it is easier to go through these stages and transform and get a new perspective on things (1990, p.132).

To be in good health or healthy is to be complete as a human being. If someone is affected by disease that unity is disturbed, making one feel incomplete, not whole, reduced as a person, different. Suffering can be caused by disease but Eriksson argues that it is also part of health and part of being human. Thus someone can be physically and mentally healthy yet suffer. Health comes from the ability to endure suffering. Therefore someone who is affected by disease can still feel that they are in good health, despite their suffering. They are enduring their suffering (1994, p. 64).

Bäckman defines health and disease according to three different types (1991, pp. 13-14):

1. The medical definition
2. The subjective or psychological definition
3. The social definition

The medical definition is objective and has its basis in biology. It uses for instance chemistry in order to diagnose diseases. One example is the use of chemistry when analyzing blood samples to determine disease. Diagnosis is based on a physical, well-defined condition. The subjective definition is determined by the subjective feeling of one's health. The individual themselves determines their own health. Therefore someone can be physically ill but feel

healthy, or appear to be in good health but feel unhealthy. Usually the subjective feeling of one's own health will determine whether one seeks medical attention or not. The social definition is defined as being in relation to the social environment. When the individual is incapable of fitting into the expectations of society they are often defined as sick or ill. This can be due to physical or mental illness. Although not considered ill, individuals may not fit into the social norm due to other circumstances such as life choices, behaviors, or experiences. A person is determined healthy according to social norms when they can work and be productive (Bäckman, 1991, pp. 13-14).

Conflicts can arise between the social environment and the individual which causes strain on the individual. Conflicts can be due to technological changes, changes in work environment or changes in home environment. Health is profoundly connected to quality of life (Bäckman, 1991, pp. 176-178).

According to Bäckman there are mainly four factors that affect people's health. These are: biological or genetical, lifestyle, environmental (meaning both social and physical environment) and health systems. Health is reached when all systems are in harmony with each other (1991, pp. 25-26). Societies create goals to promote health and wellbeing among their population. Through population statistics they look at biological factors that determine health, but also at lifestyle choices. Both international and national health programs also look at how actual physical environment but also psychosocial environment affects their population's health and whether the service given is approachable and comprehensive. This gives societies the basis for improvement within health care but also for health promotion and disease prevention (1991, p. 32, p. 37). WHO also uses statistics to describe disease prevention and health care, but also the social environment and lifestyle choices (Bäckman, 1991, p. 27, p. 36).

### **3.3 Previous Research**

In order to gain an understanding of what SBS is, what the causes can be and common symptoms of SBS, I used the search engines through the Novia library web site. I mainly used the Nelli portal database in order to access the Academic Search Elite Database EBSCO. Key

words I used were: Sick Building Syndrome, indoor air quality, ventilation, indoor environment, building related symptoms, indoor exposure. I did searches with similar words in Swedish. I found many useful articles in different types of journals. I also did searches through the Google Scholar web site. The articles I ended up using I found to be helpful in gaining knowledge of SBS that I needed in order to better understand the informants' experiences both during the interview but also afterwards when going through the transcribed material.

I have also gained knowledge through books and articles that I have borrowed from people involved in the TEMA project. The articles that I have used were mostly from between the years 2000 and 2012; however, in a couple of instances I did use older articles as well. I opted to use these articles either because they were the original source used by some newer articles or they had information that still is accurate. The reason I understood it to be accurate was because all newer material I found repeated previous information.

I used articles mainly from Scandinavia and North America. Scandinavia was relevant since the informants' experience was in Finland but the articles from North America were useful in getting an overall understanding of SBS. I excluded articles that mainly focused on children's experiences of SBS and studies focusing only on allergies or psychosocial stress among participants. I was careful not to be influenced by other people's stories and experiences prior to conducting the interviews. Books describing the methodology and theory part of my study were allowed to be older material as well.

## **4. Sick Building Syndrome**

Sick Building Syndrome (SBS) is the common name for buildings with flaws in their construction that cause people to get health issues. Often there is a combination of different sources and causes that makes a building "sick". Sometimes the construction of a building leaves harmful particles to accumulate and pollute the air. In our efforts to create energy efficient houses we sometimes instead create poor air flow which can cause health problems. Heimlich's research studies performed at different office buildings show that those affected by SBS exist in all working groups (2007, p. 2). However, where buildings have central air, in

comparison with naturally ventilated buildings, office workers are twice as likely to develop SBS (Lyles et al., 1991, p. 67; Seppänen et al., 2004, pp. 102-116).

Sometimes it is not the actual building that is the problem but it can be other factors that are not completely understood at this time. Therefore SBS sometimes also stands for non-specific building-related symptoms. Still, low ventilation rate and chemical exposure have been determined to cause symptoms among people exposed (Glas et al., 2008, p. 1297).

At this time researchers are not entirely clear on what levels of pollutant cause health problems and therefore it is still difficult to determine the exact required ventilation rate. It also seems that ventilation sometimes is the cause of the problem because it may bring in harmful particles from the outside. The other difficulty is that perceived air quality in itself is not a measurement of how good the air actually is. Often people in the building cannot detect any harmful substances through senses such as smell (Seppänen et al., 2004, p. 103).

Historically, mostly work that involves machines has been affected by work-related hazards, but in today's society even those working at offices, hospitals, schools etc. are increasingly affected by SBS, leading to increased sick days, stress, decreased productivity and overall dissatisfaction with the workplace (Lyles et al., 1991, p. 67; Seppänen et al., 2004, p. 103).

Although there is not always a clear understanding of what causes SBS, certain factors have been identified as the most common cause of health problems. Many of these sources are interconnected, meaning that the problem is not just within one source but that many sources cause a chain reaction which ultimately leads to issues with a building. It could be that ventilation causes harmful substances to be spread in a building, or it could be that high temperature inside a building in comparison to the outside causes condensation which can create bacteria and mold (Seppänen et al., 2004, pp. 102-115; Glas, 2010, pp. 14-19).

## **5. Clinical Manifestations/Symptoms**

The identifying factor of SBS is that symptoms appear or become stronger when an individual affected by SBS stays in the building, and disappear or become less urgent when the

individual leaves the building. It is not completely clear who will develop SBS but several risk factors have been determined, such as certain sex, age and psychosocial factors (Glas et al., 2008, p. 1297; Seppänen et al., 2004, pp. 102-115; Norbäck, 2009, pp. 55-58).

It is important to determine that the symptoms are not due to other already diagnosed medical conditions. However, conditions such as asthma and atopic skin may become more severe due to exposure. Also other allergies tend to be triggered due to allergens in the indoor air (Salo et al., 2009, pp. 185-194). Studies among SBS patients in Sweden have shown that symptoms often can become chronic and new exposure can worsen symptoms even further (Norbäck, 2009, pp. 55-58).

In a study done by Burge et al., office workers who reported SBS were asked about their symptoms. 57% reported lethargy, 46% reported irritations of the mucous membrane such as dry throat or stuffy nose, and 43% reported headaches (Lyles et al., 1991, p. 67).

## 5.1 Mucous Membrane Irritation

The most common symptom of SBS is irritation of the mucous membrane, such as in eyes, nose and throat. In some cases it becomes so severe that the person affected may not be able to wear contact lenses or their nose is constantly stuffed. They may also be affected by severe rhinitis that only goes away when they are away from the building or work area. Usually no clear source of the problem emerges, nor is any clear allergen found. Those affected at work usually see their symptoms clear up or disappear once they are away from work for shorter or longer periods of time, such as weekends or holidays (Lyles et al., 1991, p. 67).

Someone could also be affected by varieties of allergens that exist at work, such as dust, dust mites or fungi. Often these allergens cause allergic rhinitis or bronchial asthma. These allergens can be particularly high during times of reconstruction and remodeling and people normally not affected may react to the elevated amounts of allergens in the air (Lyles et al., 1991, p. 67).

Microorganisms such as fungi and different types of bacteria can contaminate central heating/cooling systems and cause hypersensitivity pneumonitis and humidifier fever.

Hypersensitivity pneumonitis causes inflammation of the alveoli and bronchioles due to an immune response to these microorganisms. Prolonged exposure can lead to lung fibrosis. Humidifier fever causes fever, joint aches and muscle pain. It is more common during winter months and goes away when the person is not exposed to the microorganism any more (Lyles et al., 1991, p. 68).

## 5.2 Dermatologic Symptoms

In some cases of SBS dermatologic symptoms such as rash or dry, itching and burning skin have been reported. Often these types of skin problems are more frequent in buildings with low humidity, low temperature and airborne fiberglass (Lyles et al., 1991, p. 68; Glas, 2010, p. 13).

## 5.3 Symptoms Affecting the Central Nervous System

The most common symptoms, called general symptoms by Glas, are headaches, heavy-headiness, nausea, concentration difficulties, dizziness and fatigue (Glas, 2010, p. 12). These symptoms have been linked to buildings that have a high concentration of chemicals, such as hospitals, clinics or pharmacies but also those that are newly constructed or remodeled. It can also be due to cleaning solvents, paints or insect spray that are used more or less regularly. In some cases it has been due to low level carbon monoxide poisoning due to poor ventilation or faulty building construction (Lyles et al., 1991, p. 68). Also high levels of radon, CO and CO<sub>2</sub> have been determined to affect the central nervous system. CO<sub>2</sub> is exerted by humans and ventilation needs to be sufficient even when humans are the main pollution source (Arbetsmiljöverket, 2009; Seppänen et al., 2004, p. 103).

## 5.4 Emotional and Psychological Factors

Often people who are affected by SBS feel helpless in their attempts to communicate their symptoms to others. This lack of compassion and the feeling of being misunderstood or not taken seriously can not only cause stress but take an emotional toll on the person affected. This can be considered an additional symptom of the syndrome and can be viewed as a chain reaction of the already existing symptom, and its importance should not be dismissed or minimized (Lyles et al., 1991, p. 68).

The problem in diagnosing lies in the difficulty in connecting exposure with symptoms. Since not all factors that cause symptoms are fully understood it is problematic to pinpoint what triggers symptoms. It is also complicated since different people in the same building/room may have different symptoms and the severity of symptoms may also vary between individuals. In many instances most individuals exposed do not even show any symptoms, making the individual who shows symptoms feel isolated (Glas et al., 2008, pp. 1297-1303). It is also difficult to diagnose SBS as there is no common description and definition of SBS (Glas, 2010, p. 14).

Skeptics towards SBS claim that underlying causes are not due to exposure in buildings but to either psychosomatic causes or already existing underlying medical conditions (Brauer et al., 2010, pp. 639-649). Some critics go as far as deeming SBS to be an attempt at mislabeling psychiatric disorders or even post-traumatic stress disorder (Bell et al., 1998, pp. 1135-1145).

In a study among 79 office workers in northern Sweden made by Bo Glas and several other researchers, the researchers wanted to clarify what chemical components could trigger SBS. They used three adsorbents (Carbopack B, Chromosorb 106 and Tenax TA) to study office workers with and without SBS and how chemical exposure affected them. The study result showed that even though the actual chemical compound that the office workers are exposed to is unknown there is a possible way to compare and find differences in compounds and compare the different adsorbents. This research is one step further in using chemistry to understand what causes SBS (Glas et al., 2008, pp. 1297-1303).



## 6. Factors That Can Cause SBS

In this chapter I intend to explain further some of the most common factors that can cause SBS.

### 6.1 Individual Risk Factors

There are certain individual factors and personality traits that studies have proven increase the risk of contracting SBS. Women have been shown to more often than men be affected by SBS (Glas, 2010, p. 14). Why this is the case has been debated among researchers but according to Norbäck reasons may be office environment, work tasks and personality traits that are different than those of their male counterparts (2009, pp. 55-58). Glas has in his research found that it may be because women are more vulnerable to certain symptoms such as upper respiratory diseases and skin problems. Women may also be more susceptible due to higher workloads at home (2010, p. 15). Bell et al. also point out in their research that females are more susceptible to SBS due to higher estrogen/progesterone ratios. In their research they claim that estrogen/progesterone levels play an important role in neural sensitization because of prolonged and repeated exposure to outside stimuli such as drugs, chemicals, and other health stressors. Neural sensitization occurs when the brain repeatedly and for prolonged periods of time is negatively affected by outside stimuli/stressors. This affects the brain and causes neurological damage that can affect both endocrine and immune functions. It can also influence the psyche of the person affected (1998, pp. 1135-1147).

Some researchers such as Seppänen and Fisk claim that age is a risk factor for SBS. According to their research children are for instance more susceptible to asthma and respiratory diseases due to indoor air pollutants (2004, pp. 102-115). Bo Glas also considers age a risk factor. In his research in Sweden he has found that symptoms of SBS are most common among people aged 30-39 (Glas, 2010, pp. 14-15). However, some researchers like Norbäck argue that there is no current reliable evidence that age actually would be a risk factor in itself (2009, pp. 55-58).

Those individuals who have already been diagnosed with atopic skin and allergy and asthma are more prone to be affected by SBS (Norbäck, 2009, pp. 55-58). However, Glas argues that due to their preexisting condition they may state that it is due to SBS although SBS may not be the actual cause. Their condition may still worsen due to harmful exposure in a building (2010, p. 15). It can be determined; however, that exposure to several different types of mold can trigger asthma or allergy. Studies have shown that asthma is the leading cause of absence among school-aged children and children in daycare facilities. Interestingly, it also accounts for one of the leading health problems among teachers and others working within schools. Because children's sensitivity towards allergens develops in early childhood this exposure can lead to lifelong health issues. Salo et al. have found significantly few studies that focus on the connection between asthma and allergy and exposure in schools and daycare. It appears, according to Salo et al., that most studies have paid attention to the characteristics of exposure rather than to cause and effect (Salo et al., 2009, pp. 185-194).

Also those who have neurotical tendencies, are more anxious and do not handle stress well are according to many researchers more affected by SBS. A study of 171 female office workers found that anxiety, anger, distress, depression, self-consciousness and low self-esteem had an impact on how these women's health was affected by the ventilation in a building (Glas, 2010, p. 15). If the work environment is deemed as non-supportive and workers feel a lack of control the frequency of SBS increases. Therefore, according to Glas and Norbäck, the psychosocial environment has an influence on the amount of personnel affected by SBS (Norbäck, 2009, pp. 55-58; Glas, 2010, p. 15). Stress seems to not be a factor in the frequency of SBS if social support is present but researchers are not completely clear on exactly how psychosocial factors in themselves can cause SBS. Still, it has been concluded through research that there is an association between frequency of SBS and psychosocial factors such as job demands, lack of social support, stress, and work-related depression and anxiety (Glas, 2010, p. 15). Critics such as Brauer and Mikkelsen claim that those individuals affected by negative psychosocial work environment tend to over-report problems about the indoor environment. They studied 3,281 employees in 39 randomly selected workplaces that had no known indoor problems. They wanted to understand whether the psychosocial risk factor played a role in the employee's perception of the indoor air quality. They came to the conclusion that individual factors such as sex and previous allergies, and psychosocial factors such as job dissatisfaction and a "general tendency to complain" affected how employees

perceived the indoor environment. According to their results young women who smoked and had hypersensitivity tended to complain more about the indoor environment although the building actually was not deemed “sick”. In fact, they came to the conclusion, based on their research, that actually sick office buildings are not a common problem in Denmark anymore (Brauer et al., 2010, pp. 639-649).

Interestingly, nobody has found any correlation between factors such as obesity, regular physical exercise, marital status or educational level and frequency of SBS. However, studies both in the U.S. and Scandinavia have found that SBS is more commonly found in multifamily dwellings and public buildings than in private houses (Norbäck, 2009, pp. 55-58).

## 6.2 Combustion Pollutants

Heating and cooling devices that do not function properly or are incorrectly installed can produce harmful levels of carbon monoxide, nitrogen dioxide and sulphur dioxide. These pollutants can cause symptoms such as headaches, dizziness, and fatigue. Some paint strippers and household chemicals can also form carbon monoxide (Heimlich, 2007, p. 1).

## 6.3 Room Temperature

Studies have shown that room temperatures above 22°C not only cause symptoms such as tiredness and headache but also increase mucosal irritation (Norbäck, 2009, pp. 55-58). According to Seppänen and Fisk, high room temperature has been shown to increase the frequency of SBS (2004, p. 111). The connection between temperature and humidity is also relevant. Studies have shown that symptoms such as headache and fatigue increase while the ability to think clearly decreases when the temperature is between 20-26°C with a humidity of 40-60%. However, symptoms such as dry skin, rash and nasal congestion decreased when the humidity in a room was elevated. On the other hand, symptoms like sneezing and nasal congestion increased if the temperature was also increased (Glas, 2010, p. 17).

## 6.4 Air Pollutants

Biological air pollutants exist naturally all around us, both inside our buildings but also outside. Examples of biological air pollutants are dust, dust mites, dander, molds, certain bacteria and fungi. Some of these can be caused by us or our pets. However, sometimes they can also be the result of poor building construction, flooding or inadequate ventilation, particularly in bathrooms and kitchens. Other sources of the problem can be humidifiers, air conditioners and dehumidifiers. Biological air pollutants are known to be able to cause infections, hypersensitivity diseases and toxicosis. Toxicosis is when biologically produced toxins cause a toxic effect on the human body (Heimlich. 2007, p. 2).

Pollen is a common allergen and can be brought indoors by the ventilation system but also on clothing (Seppänen et al., 2004, p. 109). Dampness causes mold and studies have shown a 50-100% increase in SBS when people report building dampness (Norbäck, 2009, pp. 55-58). Dust mites require humidity in the air above 55% in order to survive and thus, dust mite sensitivity tends to occur more often among people who spend time in rooms with higher humidity levels. Therefore negative reactions to dust mites are more frequently found in humid areas such as Brazil or the southern states in the U.S. but less commonly in Scandinavia (Salo et al., 2009, pp. 185-194). Chemical air pollutants such as radon or CO are highly toxic but difficult to detect due to their lack of odor (Seppänen et al., 2004, p. 103).

Studies have shown that exposure to fungi in buildings causes particularly respiratory problems such as asthma. Researchers still do not completely understand the reason for this but it appears that fungi contain multiple biologically active molecules that can cause an inflammatory response in humans, resulting in allergy or respiratory morbidity (Salo et al., 2009, pp. 185-194).

## 6.5 Volatile Organic Compounds and Heavy Metals

Volatile Organic Compounds (VOCs) are gases that are released from both solid material in buildings but also from liquids and gases found in a household or in buildings. These gases can be emitted from common household cleaners, but also from paint, paint thinners, copiers

and printers, glues, markers etc. VOCs can also be due to human emissions (Norbäck, 2009, pp. 55-58; Seppänen et al., 2004, p. 110). Studies have shown that indoor bio aerosols, dust and other airborne particles increase SBS. Recent studies among office workers show that prolonged exposure to paper dust and the fumes from printers and copy machines increases the risk of contracting SBS (Norbäck, 2009, pp. 55-58). Through the ventilation systems fumes and other harmful particles from the outside can also be spread and affect people in that building negatively (Seppänen et al., 2004, p. 103).

In the past formaldehyde was used as insulation in buildings, but it can also be found in building material such as plywood paneling, adhesive for carpets, backings and finishes. Also carpets, wall coverings and paint can contain formaldehyde. Formaldehyde is also commonly found in chemical household products such as cleaning supplies, detergents, perfumes, soaps etc. Formaldehyde has been determined to be a major irritant for humans and can also be one cause of SBS (Heimlich. 2007, p. 2).

Phthalates in indoor dust has also been determined to cause asthma and allergy, particularly in children exposed to it (Norbäck, 2009, pp. 55-58). Several animal research studies have shown that volatile formaldehyde, some pesticides and solvent toluene are able to promote neural sensitization. Sensitization is when the responses in the host become amplified due to a prolonged and repeated exposure to health stressors such as chemicals like formaldehyde. Since it affects the brain, it disturbs mood, behavior, and endocrine and immune functions. According to research done by Bell et al., females are more susceptible to chemical stimuli (1998, pp. 1135-1147).

A controlled exposure study done by Laumbach et al. investigated whether there is a link between exposure to chemical contaminants and psychological stress, making symptoms not only more likely but the effect is both physical and behavioral. The study objects were exposed to low levels of diesel exhaust (DE) and some were exposed to stressors in the form of public speaking. Many objects displayed eye, nose and respiratory irritation but also nausea, fatigue, memory impairment, difficulty in concentration, vertigo and abdominal problems. However, the link between psychological stress and exposure to DE could not be determined, which seems to agree with Glas' findings regarding stress and effect of exposure (2011, pp. 945- 950; Glas, 2010, p. 15).

Heavy metals such as lead can be found in paint that was used in the 1940s. Although it has been banned since 1978 it can still be found in paint or pipes in older buildings. Lead in itself does not cause any harm but if it is ingested it can cause lead poisoning. In the past the heavy metal mercury was used in indoor latex paints and inhaling its vapors could cause serious health problems (Heimlich, 2007, p. 2).

## 6.6 Ventilation and Air Flow/Air Conditioning

When a building does not have a functioning and well planned ventilation system it creates pockets where pollutants can accumulate. The pollutants are not forced out of the building, which results in air that is not exchanged and flowing as it should. This is a major problem particularly in well insulated buildings where outside air is sealed off due to high or low outside temperatures. When air exchange functions poorly pollutants can overtime build up inside a room or entire building, creating a space that causes symptoms to occur among those who spend time in that area (Heimlich, 2007, p. 1).

Studies have also shown that in buildings with air condition, if the ventilation rate is less than 10 liters per second and person, there is usually more symptoms of SBS among the personnel. The symptoms are usually affecting skin and mucous membrane (Burge, 2004, p. 187). According to Seppänen and Fisk, research has shown that the prevalence of SBS symptoms increases by 30-200% if a building has air conditioning, in comparison with naturally ventilated buildings. Studies also show an increase in symptoms in mechanically ventilated buildings in comparison with naturally ventilated buildings. These findings are statistically significant in determining cause and effect and cannot be explained by chance or other factors. It is important, however, to highlight that if the HVAC system (Heating, Ventilation and Air Conditioning) is well maintained symptoms are less frequent (Seppänen et al., 2004, p. 111).

Ventilation and air conditioning units are often connected, which makes the problem even more complex. Not only does ventilation spread harmful particles from both outside and inside around but ventilation can also spread virus and bacteria. It is also common that poor ventilation in a room or building causes fatigue, irritability, tiredness and difficulty in concentration (Seppänen et al., 2004, p. 103). According to the Swedish governmental agency

Arbetsmiljöverket, inadequate ventilation flow can cause SBS. The ventilation rate needs to be adjusted depending on the number and strength of pollutants in a room. Guidelines recommend 7 liters per second and person for sedentary work. If there are many pollutants, an additional 0.35 liters/second and m<sup>2</sup> is recommended (Arbetsmiljöverket, 2009).

Research done by Seppänen and Fisk in 2002 shows that the risk for symptoms increases up to three times if a building has air conditioning or is mechanically ventilated, in comparison to naturally ventilated buildings. Their later research also shows a decrease by 29% in SBS symptoms if outdoor air flow is increased to 25 liter per second and person in comparison to the minimum of 7-10 liters per second and person (Seppänen et al., 2002, pp. 98-112; Seppänen et al., 2004, pp. 102-116).

## **6.7 Relative Air Humidity and Dampness**

Studies have shown that both low air humidity and high air humidity can cause symptoms. Low air humidity is mostly known to cause upper respiratory, dermal and ocular symptoms whereas too high air humidity does not in itself cause symptoms but indirectly does due to microbial growth because of water condensation (Norbäck, 2009, pp. 55-58). Humidity above 50% also causes an increase in dust mite levels and ventilation can cause the spread of dust mites, increasing allergic symptoms among those sensitive to dust mites (Seppänen et al., 2004, p. 103).

Dampness due to water from leakage or high humidity can cause VOCs to be formed, causing symptoms, but it can also cause growth of microorganisms, bacteria and mold. Respiratory symptoms seem to be more common in damp buildings (Seppänen et al., 2004, p. 108). Spores from mold can cause serious conditions such as allergic alveolitis (Glas, 2010, p. 19).

## **7. Expected Procedure when Suspicion of SBS**

If there is a health problem due to a building or indoor air quality the employer is responsible by Finnish law to investigate and take adequate measures to improve the situation for the employee/s and sanitize the building. The safety and wellbeing of the employee are granted by law and the employer is required to follow certain steps to make sure that both the health of the employee and the building are thoroughly investigated.

Through occupational health services the cause of the health concern is examined and diagnosed. According to Finnish law this includes symptoms caused by poor ventilation, harmful chemicals, moisture damage and mold.

The employer is then responsible for contacting the landlord of the property and demand a thorough investigation of the property and that sanitation or reparations are done in a timely manner. This process is documented and shared with occupational health services who then determine if another worksite needs to be found (Arbetarskyddsförvaltningen, 2009).

## **8. Methodology**

In this chapter I will explain in more depth what methods I have used in my study and why I have opted to do a qualitative study.

### **8.1 Qualitative Study**

Through a qualitative approach it is possible to gain knowledge and understanding of the lived human experience, which is something that cannot be measured or quantified. In social sciences the researcher wants to gain knowledge of culture, human values, human relationships and interactions, all of which are things that cannot be quantified or described using only quantitative methods. Using this type of method in nursing research is suitable when the aim is to describe the subjective feeling of a patient or their family and when the purpose is to understand the patient's interpretation of a phenomenon. Qualitative research



focuses not only on the social experience in itself but also on understanding where the experience derives from and how it affects human conception of reality. Through qualitative research the researcher begins to see patterns and recognize how phenomena affect people differently based on their life experiences and social structure. The qualitative research findings are not, however, to be generalized nor can they be controlled or measured as in the use of quantitative research (Streubert, 1999, pp. 1-5).

I chose a qualitative method for my research since my aim is to describe and understand the lived experience of those that have been affected by SBS.

## 8.2 Phenomenology

Phenomenological nursing research looks at the lived experiences of patients and/or their families. It is a model of systematic research of the everyday lived experiences using both philosophy and theory as the guiding methods. Phenomenological research focuses mainly on understanding a sociological phenomenon and the meaning of it (Morse, 1991, pp. 26-29).

When using phenomenology as a method for research it focuses on the subjective experience of those that you interview or study. The researcher wants to understand opinions and personal interpretations, attitudes and convictions, and the subjective feelings and emotions of the participants. The researcher aims at understanding rather than measuring and at describing instead of analyzing. Due to the subjective elements of phenomenology it has been criticized by those who value statistical measurements of phenomena (Denscombe, 2009, p. 109).

Phenomenologists often deliberately try not to let their previous knowledge of a phenomenon influence their research. In some cases phenomenologists wait until choosing their theory in order not to have preconceived opinions about the phenomenon they are studying. When choosing a theory they choose it on the basis of what aspect of a person's life they aim at studying. They often use a framework of philosophy as guideline in their research. This framework keeps the researcher focused on the subjective experience in order to avoid the lived human experience to be a construction by an observer (Polit et al., 2012, p. 139).

Phenomenology asks the question of the meaning of a human experience based on an individual's subjective feeling about an experience or phenomenon. Phenomenologists want to find truths in the stories people tell about their experiences. Phenomenology is particularly useful when studying something that has not been clearly defined or conceptualized. It can be used when the researcher aims at understanding the meaning of a lived experience such as suffering, quality of life or feeling of pain (Polit et al., 2012, p. 494).

Through the use of phenomenology the research aims at letting others see what the study objects see. By using rich, detailed and colorful descriptions the researcher wants to share the experience of the study objects with the reader (Polit et al., 2012, p. 495).

The most common methods used in phenomenology are descriptive phenomenology (Husserlian phenomenology) and interpretative phenomenology, also called hermeneutics or Heideggerian method. All phenomenological methods use in-depth interviews where the researchers are interested in understanding the experience of a phenomenon (Polit et al., 2012, p. 495).

### **8.2.1 Descriptive Phenomenology**

I have opted to use descriptive phenomenology since I aim at describing the lived experience when affected by SBS, how SBS affects the informants' quality of life and how they feel they have been met by health care professionals and employers but also by family and friends.

Descriptive phenomenology mainly focuses on descriptions of human experience. Human experience involves an individual's subjective senses such as seeing, hearing, feeling, remembering, acting, evaluating and deciding. When using descriptive phenomenology the researcher uses four steps to identify and also prevent preconceived opinions and beliefs regarding a phenomenon. These steps are bracketing, intuiting, analyzing, and describing. Bracketing is a method used to reflect on the studied phenomenon throughout the research in order to avoid that any predetermined opinions affect the study. The researcher wants to get data that is pure and not influenced by others' opinions or beliefs on the matter. Often the use of a reflective journal is helpful in the bracketing process. In the journal the researcher can identify areas where they may be biased and illuminate what values, opinions and feelings

they may already have which could possibly affect the research. In the reflective journal the researcher can also keep track of new findings and identify potential conflicts of interest. When the data analysis is made the researcher can reflect on the findings, and on whether the literature used supports these findings. In the intuiting phase the researcher has to focus on being open to the meaning of the experiences of those that are participating in the study. When analyzing in descriptive phenomenology the researcher wants to understand what the experiences mean to those participating in the study. The researcher tries to find statements that can be divided into categories of importance. The last phase is the descriptive phase when the researcher has found meaning and understanding of the phenomenon that was studied (Polit et al., 2012, pp. 495-496).

### **8.2.2 Phenomenological Data Analysis**

Meaning condensation which was developed by Giorgi in 1985 is a form of analyzing in phenomenological studies. Meaning condensation is well suited for analyzing rich and in-depth interviews and it focuses on finding units and categories that occur naturally throughout the interview. Therefore the categories become clear once the researcher starts to read through the material and are not determined prior to the interviews (Kvale, 2007, pp. 106-108). The criticism this method has received is mainly that it relies entirely on the researcher's ability to analyze the data. A similar method is Colaizzi's phenomenological analysis method. It is similar in that it also looks at extracting significant statements as a basis for meaning formulation, but the major difference is that once the description has been formulated it returns to the participants for a validation of the findings. There is also another method for analyzing phenomenological data, which was developed by Van Kaam already in 1966. Van Kaam uses expert judges to validate the descriptive statements in the beginning of the analysis but also throughout the study in order to avoid vagueness and overlapping expressions by the participants (Polit et al., 2012, pp. 565-567).

My previous understanding of the topic was limited and I had to do thorough research in order to understand what SBS is, what causes it and its symptoms. Through my research I was also able to better understand the problem with diagnosing symptoms due to SBS. I have opted not to use research articles about other experiences of living with SBS since I did not want my

research to be influenced by other people's life stories. Instead I focused on merely listening to the informants' experiences and let their stories be the core of my study.

## **9. Conduction of the Study**

This thesis is a qualitative study based on interviews. The interviews have been interpreted using descriptive phenomenology.

### **9.1 Data Collection**

I did in-depth interviews with two people. The informants' contact information was given to me by my teacher. The informants knew that I would contact them and had agreed to participate in my study. I contacted the informants and scheduled the interview based on their availability. I also explained to them the purpose of my interview as being part of the TEMA project and that their interviews would be the basis for my study. I also explained to them what the TEMA project is. They both agreed to participate in the interview. Since the aim was to perform in-depth interviews I allowed the informants to choose a site for the interview in order to make them feel as comfortable as possible. The only criteria I had was that it would not be too noisy since I recorded our conversations. The informants knew that what they were saying would be recorded. One informant opted for a room in the school where he works and the other a restaurant close to her home. That interview was done in the outside seating area and a bit separated from guests at the restaurant. The interviews were done in Swedish since both participants are Swedish-speakers. The participants spoke two different types of Swedish dialect. The recorded conversations were transcribed in the same way as the informants spoke, using dialect. I let the informants know that they could contact me if they had further questions or wanted to add to something and I also let them know that their participation would be anonymous. Lastly I explained to them that if they want they can read my thesis once it is approved. They also had the option to withdraw their participation if they needed to, without any questions asked.

### 9.1.1 Interview

When conducting an interview the interviewer needs to show genuine interest and understanding of the interviewee's story. This is not only shown through the questions we ask but also through our tone of voice, our gestures and our posture. It is important that the interviewer does not come across as judgmental or critical since that can cause the interviewee to feel vulnerable and uncomfortable which may result in them not answering any more questions. The preferable way to start an interview is by first asking some fairly neutral questions and then move on to questions that may be more in-depth or more sensitive. It is imperative to end the interview with questions that are neutral. It is also important to avoid questions that are too long or complicated, questions that will lead to a certain expected answer, questions that have more than one question in the same sentence or questions that can only be answered with yes or no (Patel et al., 2007, pp. 71-74).

This is a phenomenological study that aims at getting a better understanding of the participants' experience with SBS. It is based on their stories and although I used certain questions the idea was to use these questions to facilitate conversation and open up for their stories and not limit them. The questions were therefore broad and open-ended and the informants were able to use these questions as a guide in telling their story. The interview was more like a conversation rather than a standard interview. The informants were allowed to highlight what they felt was important without a timeline and without being limited by my questions. The interviewer's role was to listen, clarify, and ask questions when necessary. Most of the questions rose naturally throughout the conversation/interview. The interviewer did not push for answers if the informants did not feel like discussing something more in depth.

### 9.1.2 Translation

Since this is a phenomenological study it is important to give the reader an inside view of the participants' experiences. In order to give as colorful and truthful descriptions as possible I have used quotes from the informants throughout the results section of this thesis. Since I am

bilingual I have translated the Swedish quotes into English myself. The difficulty when translating spoken language, particularly dialect, is that the translation is not always word for word since this sometimes would not make any sense in another language. Therefore, when absolutely necessary, I have had to make small changes in the English in order to be able to clarify what the informant says. Also when using certain phrases or proverbs they cannot always be directly translated but the English version of that proverb has to be used or the text has to be loosely translated into English. For transparency I have put the Swedish transcribed quote in brackets next to the English translation.

## 9.2 Data Analysis

I opted to use the concept of meaning condensation created by Giorgi as a form of highlighting and rephrasing what the study participants' experiences of living with SBS have been. According to Kvale meaning condensation will rephrase the information given by the informants into shorter statements and phrases. It is important to first go through the transcribed material thoroughly to get a sense of the entire picture. Categories will arise naturally from the text and it is at the researcher's discretion to determine these “meaning units” based on the participants' experience. The researcher needs to gain a psychological insight through these meaning units. These units/categories are then divided into themes that have their basis in statements given by the informants as understood by the researcher. Then these themes are brought into the specific purpose of the study, what the study aims at investigating. In the analysis these themes are interconnected to form an overall description of the situation. For meaning condensation to be successful the informants should be given the opportunity to tell their story in their words and language without any limitations. The result should be a rich and nuanced story about the lived experience (Kvale, 2007, pp. 106-108; Polit et al., 2007, p. 566).

I aim to use the categories that have arisen in the results chapter of my thesis as the foundation for my interpretation. I aim to use both Eriksson's theory on suffering and Bäckman's theory on health when interpreting the data that I have collected from the participants. The aim is to understand the participants' experiences through the theoretical framework of Eriksson and Bäckman.

## 9.5 Ethical Considerations

SBS is often difficult to diagnose and since it can often be taken as caused by other factors such as job-related stress or discomfort it is important that those that are participating in the study feel that their health concern is taken seriously. I do not want to single out those that participate in this study and make their situation worse.

Since interviews are based on the interaction between informant and interviewer our understanding of human conditions is an interpretation of what the informant says. By exposing the private lives and making them public we as researchers have to carefully navigate ethical and moral waters in order to avoid ethical problems and moral dilemmas. Not only do we have to be careful how we interpret the words spoken but we also have to serve scientific interest with our study and hopefully increase the knowledge of human experiences (Kvale, 2007, pp. 23-24).

Kvale describes seven stages to keep in mind when doing an interview.

1. Thematising, not only should the research fill a scientific gap but it should also take into consideration the value of improving situations for humans.
2. Designing, to make sure when designing the study that you have the informed consent of the participants of the study and reassure confidentiality for the informants.
3. Interview situation, to make sure that the interview is well thought through, taking into account the stress or emotional well-being of the informants.
4. Transcription, to make sure that the informant's confidentiality is protected and make sure that the transcription is a copy of the verbal statement of the informant.
5. Analysis, the researcher needs to consider at what depth the interviews should be analyzed and should the informant be able to comment on how their words are interpreted.
6. Verification, the researcher is obligated to report information as accurately and truthfully as possible.
7. Reporting, the researcher needs to consider what the potential consequences will be for the interviewee when reporting the findings to the public arena.

Additionally, it is important to consider potential ethical issues that may arise already prior to performing the interview and it is also important to consider how the interview may be questioned and what the impact may be for the informants (Skvale, 2007, p. 24). My aim was to follow the steps mentioned above to secure the research as being ethically sound.

Since the ones participating in the interview are doing so voluntarily, it is important to make sure that they understand the purpose of the interviews and why we value their participation. I needed to make sure that the interviewees understood how the interviews were going to be used and that if they want they can read the end results. Since their participation is anonymous there will be nothing in the end result that can identify the interviewees. Therefore I opt for the participation to be confidential, meaning that only I, the interviewer, will know who have been interviewed and there is nothing else that will make the participants recognizable. Prior to conducting the interviews the participants were provided with all the information needed (Patel et al., 2007, pp. 69-71).

## 10. Results

The approach I have taken in this study is to describe the lived experience and subjective feelings of those that participated in the study. Since the study only focused on in-depth interviews with two people I did not feel that it was sufficient participation to make any general conclusions based on the results of the study. I aim to describe the feelings of the participants and the results are best presented by categorizing and highlighting experiences.

When doing a phenomenological study the researcher looks at themes or categories instead of research questions. These themes or categories are not determined prior to conducting the study although the aim or purpose of the study is. Instead, categories/units will arise naturally from the text which will be the foundation for the themes that are explored and described more in detail.

The aim of the study was to describe the subjective experience of SBS by two individuals. Throughout the study the following themes resurfaced: To live with SBS, affirmation and response, and the struggle and outcome.



Interviews were made with two individuals who are not connected to each other. The two in-depth interviews took place during two separate occasions. The informants' stories had both similarities and differences. Throughout the interpretation I have highlighted their individual experiences in order to give the reader a better understanding of their experiences. The interviews were done in Swedish. The interviewees spoke different Swedish dialects and the transcribed interviews were thus transcribed in the dialect they spoke. I have used quotes from the participants that I have translated into English. I have put the original wording in Swedish dialect as transcribed in brackets for transparency.

## 11. The Results of the Interviews

The following themes arose from the transcribed material: **To live with SBS, affirmation and response** and **the struggle and outcome**. Within these themes, categories emerged that support the themes. Each category has its own subheading where quotes from the interviews are given in order to highlight the experience of the participants.

### 11.1 To Live with SBS

The first theme, to live with SBS, is highlighted by the following emerging categories: **How SBS affected their health, the quality of life** and **support from family, friends and co-workers**. Both participants had previous medical conditions before they were affected by symptoms due to a building. Their previous medical conditions had not significantly affected their lives or their quality of life before. One participant had a condition that affected his lung capacity and the other one had allergies and asthma since childhood. Both participants in the study realized early on what the causes of their new symptoms were. In one case it was tree dust and in the other case it was mainly mold that caused symptoms to resurface.

The first theme focuses on the appearance of symptoms, how these symptoms affected their health and how they affect their daily life. It shows the struggles the informants go through on

a daily basis when affected but it also shows how family, friends and colleagues react to the symptoms. Theme one also looks at the quality of life of the informants.

### 11.1.1 How SBS Affected Their Health

One informant had been working in the same building for the past twenty years and his previous medical condition had not affected his health until three years ago. During the past three years he noticed that he was having increasing difficulties breathing in certain areas of the building but he also noticed that he was getting a runny nose, eye problems, headache and tiredness.

*“I get tired. Runny nose, eyes that hurt, and my blood pressure increases.” [“Jag blir trött. Snuva, sjuka ögon, blodtrycke stiger”]*

He also noticed that his blood pressure increased when he was working and decreased when he was on sick leave or during vacation.

*“Well, sure I feel better; [during summer vacation] I decreased the blood pressure medication by half” [“Nå, no mår ja ju bättre, har minska på blodtrycksmedicineringen med hälften”]*

The other informant had had allergies since she was little. The allergies she had were to cats and dogs, pollen, and grass. She also had asthma but not severely and only needed to take asthma medicine occasionally if she had an asthma attack. She did not take allergy medicine on a regular basis either. Until 2001 she did not feel like her asthma or allergies had affected her life significantly.

In 2001 when she started working at a school she began to feel overly tired, and she felt that she could not deal with the noise in the school. Other symptoms she experienced were difficulty breathing and ongoing headaches and moodiness.

*“Tiredness and difficulty breathing and I also felt that my good mood completely disappeared. Difficulty breathing and bad temper.” [“Trötthet och tungt ti andas tå och ja känd ju också att humöre försvann riktigt kapitalt. Tung andning och dåligt humör”]*

After exposure to mold at the school her symptoms seemed to escalate, increasingly getting worse, and she started to have constant difficulty breathing, headaches, itchy and watery eyes and being constantly hoarse. These symptoms are now part of her daily life.

*“I usually say that I have a hard time 365 days out of the year, 24 hours out of the day, and I don't think I will ever get back to the time before, I will never get back, there is nothing I can do, if you have mold or toxin in your body, and then it will stay forever. You have to accept that the disease will never go away” [“Ja brukar säg att egentligen har ja jobbit 365 dagar i åre, 24 timmar i dygne, ja tror aldri ja kommer tillbax ti hande tiden, ja kommer aldri tillbax, int finns e ju na, har du hede mögle elo hede som skapar hede toxine så, e finns ju för evigt kvar. Man måst accepter att man har en sjukdom som int kan försvinn.”]*

Both informants describe symptoms such as watery eyes, runny nose and breathing difficulties when exposed. However, one informant seems to be more sensitive than the other.

### 11.1.2 Quality of Life

Both informants feel that their quality of life is affected due to symptoms. They express tiredness that affects their social lives.

*“Hmm, the last year I have worked, but I have only worked and then slept, gone right to bed when I got home. Well, I haven't had any energy, I haven't had anything else.” [“Ööh, dehe sista åre ha ja no jobba, men ja har bara jobba å sovi då, gått å sov då ja kom heim. Nå man har inte orka int, int har man ju haft så myki annat”]*

Both of them express how feeling constantly ill causes them to have to take more medication.

*“Yes, I started to go and get more medicine, and they didn't understand at the health center why everything was getting worse and why I needed stronger medicine, I just didn't get any air and my eyes started to itch and I got headaches.” [“Ja börja hämt mera mediciner och di försto int på hälsocentralen varför allt blev värre och varför ja sku ha starkare mediciner, ja fick int luft och e börja kli i mina ögon och ja fick huvuvärk”]*

When on vacation or sick-leave, or when not exposed to factors that cause their symptoms, they both feel much better and thus their quality of life also improves.

*“I took vacation and I was home some extra time and I felt really good...when I started again the hoarseness came back and I had really difficulty breathing.” [“To ut en tjäna semester åså va ja hem lite extra åså mådd ja jätte bra.....ja börja pånytt och genast kom hesheten tibak å ja fick tyngre å andas.”]*

One informant has also due to prolonged exposures to mold developed other health issues, such as sensitivity to formaldehyde. Since formaldehyde exists in ordinary products such as perfume, detergents, cleaning products etc., she is no longer able to be around people without getting trouble breathing.

*“Yes, I have felt really sick due to all the particles. The children, we have small surfaces, cramped space, and poor air quality. It has been like, I have noticed which kids have furry animals at home. Cleaning supplies such as polishes, hand soap, one notices what contains formaldehyde” [“ja har mådd dåligt av alla partiklar. Alltså barnen, vi har jätte lite utrymme, trångt, dålig luft. He har vari, man har känt vika barn som har pälsdjur där heim. Städmedel, som skurmedel, handtvål, sama som hede att man har känt att aa, i hede finns e förstås tå formaldehyden i å hande”]*

This affects her ability to have an ordinary job but it also limits her ability to do ordinary things such as shopping, going to the movies or being around others. This limitation isolates her and affects her quality of life. The other informant only feels affected when he is in one particular room and has not been affected by other buildings and rooms.

### **11.1.3 Support from Family, Friends and Co-Workers**

Being supported by others seems to play a huge role in the wellbeing of particularly one of the participants. It gives the participant the reassurance that what she feels is real and that her failing health is not something that she imagines but is also obvious to others.

*“Of course those I have worked with, like personnel and work colleagues, have always been understanding and always said that they can tell by looking at me since my eyes*

*are swollen like some balloons.” [“Och förstås alla som har jobba me, som personal, som jobbar kompisar he har allti vari förståend och har no allti sagt att nää, e syns no på dej att e ögon e ju uppsvälld som na ballonger”]*

Support from others affected by similar symptoms due to building issues also gives the participant an opportunity to discuss her symptoms with others who truly understand what she is going through.

*“And we are several who have the same problem, so we call each other and discuss and then I get the confirmation that, 'yes, I wasn't alone with that thought and you think like me'.” [“Åså e vi ju faktiskt flera som har samma problem, så vi har ringt varann och diskuterar så får man ju bekräftelsen på 'jä, int va ja ju ensam om hande tanken int och du tycker ju som jag å'.”]*

The other informant feels, however, that his health is more of a private issue and that although his family and friends know about his symptoms and the issues he has had with his employer, he does not feel comfortable discussing it any further with others.

*“Well, it's not like you go and discuss that much with your colleagues about things like this...” [“Nåå, int går man väl och diskuterar så myki me kollegor om såndär...”]*

It appears that they both feel that support from others is important but one informant finds that it is enough when close friends and family are knowledgeable about his health and the other feels that she finds comfort in others with similar health issues.

## 11.2 Affirmation and Response

Theme two highlights how the informants feel that they have been met by health care professionals and employers and whether they have received the support and recognition they expected. The following categories emerged in the informants' stories: **Expectations from health care professionals and employer, to not be taken seriously and to be taken seriously**. Theme two discusses the affirmation and response the informant received and what impact this has had on them. It also discusses what the informants think the reasons for the lack of response may be.

### 11.2.1 Expectations from Health Care Professionals and Employer

Both informants expected their employers to take their symptoms seriously and take adequate measures to improve the building condition and make sure that the issue with the building was resolved. Both informants seemed well informed of their rights by Finnish law and of what expectations they could have of their employers. They also expected that this process would go faster and more smoothly than it actually has. If anything at all was done the process took too long and both of them found that it sometimes almost felt as if the employer was waiting for them to leave their job so that the employer would not have to resolve the issue.

*“Yes, it is almost as if they wait for you to give up.” [“Jaa, e je som att di sku vent ut en tills man ger opp.”]*

The informants think that part of the reason for nothing getting done is the high costs involved in sanitizing a building. They also feel that one reason for nothing getting resolved is the lack of someone taking responsibility for the issue.

*“There is no one who takes on the entire responsibility. And then they throw it between municipal departments...” [“E finns ingen som tar helhetsansvar. Åså bollar di e mellan kommunala maskiner...”]*

They also expected health care professionals to have done a more thorough investigation of their symptoms. The informants felt as if health care staff only looked at their previous diagnosis as being the culprit of their symptoms and thought that these new symptoms were not due to something else, but in fact part of their already existing condition.

*“They said it was my underlying disease...” [“Di sa väl att e va grundsjukdomen...”]*

Although both of them were clear on the cause of their symptoms they both feel that part of the problem with health care is due to overworked staff that do not have the time and energy to pay good attention to their patients.

*“We have had two doctors, but there have been five or six nurses, no-one has been on-going, they don't know anything. They have so much work that they don't have the energy to be engaged.....I feel like they have too much work that they don't have the energy.” [“Vi har ju haft två läkare, men hälsovårdarna har vari fem eller sex, e har*

*int vari nån fortgående, int känner di ju till nånting. Di har så myki jobb så di orkar int engager.....Jag upplever att di har för myki job så di orkar int.]*

They also feel that the only time health care professionals saw a connection between the symptoms and the building was when the health care professional was specialized in the field or particularly interested in for instance allergy or asthma.

*“He was a good doctor. Too bad I can’t see him anymore. There you see the difference between a general practitioner and specialized doctor. He understood and he got it, he was more like a good judge of character and you could exchange opinions and such things, there was no hierarchy between us. He made thorough tests and then explained how the body functions and during a year I went to see him probably five or six times.”*  
*[“Han va en bra läkar, synd man int får ga ti han na meir. Där så man skillnaden mellan en allmänpraktiserand och en specialist. Han fösto och han fatta, ha va mer som en människokännare och man kuna byt åsikt me an å allt sånde, e va ingen rangordning mellan oss. Han gjord ordentliga tester och förklara sedan hur kroppen fungera och under ett år va ja säkert ti han en fem, sex gånger.”]*

Both informants expected their health symptoms to be the foundation for more profound investigations of the rooms that affected their health. Both of them feel that it is the employer’s responsibility to follow up and take adequate measures to improve the building.

### **11.2.2 To Not Be Taken Seriously**

The informants feel that their symptoms have not been always taken seriously by employers and health care professionals. This feeling of not being taken seriously affects the mental wellbeing of the participants. Both of them have felt frustrated, angry, disappointed and sad as what they feel seems to be questioned and not something real.

*“Well, it breaks you down a bit when they don’t care. It is easier to get sick-leave and then they take a substitute, no ... I just don’t get their staff policy...”* [*“Nåå, lite knäckande ere om di int bryr sej. E je enklare att bli sjukskriva åså tar di in nån vikarie åså nåä...ja förstår int personalpolitiken ja...”*]

The informants feel that it is easier to have a concrete health issue that is well defined and easy to diagnose. If you have a diagnosis you are able to get the help and support you need but without the diagnosis your health issues are looked at as being something psychosomatic.

*“So I had to go to the health center to a general practitioner and he was kind of a bit... he thought that something was wrong mentally, that I was imagining all this. He said it, he said, 'hey shouldn't you maybe go and see a psychologist?'” [“Så då va ja tvungen att gå till hälsocentralen och en allmän läkare å han va ju lite såde...han tyckt ju tå att ja had fel me psyke att ja inbilla mej och att dehär att....han sa de, han sa 'hödu, ska du kanske gå ti en psykolog?'”]*

Both informants have had similar experiences of not being taken seriously. When the informants are not getting the affirmation they expect it affects their psyche and mental wellbeing.

### 11.2.3 To Be Taken Seriously

It seems as if it is not as common that the participants in the study experience that their health issues are taken seriously by health care staff and employers but when it happens it makes the participants feel supported and taken care of. It also reassures them that they are sane and that what they feel is real.

*“He [the doctor] said that there is only a small percentage that can show that they have allergies against mold, since the majority is only super-sensitive and that is the problem, the credibility, since people may say that they are allergic but they can't prove it with patch test or something like that, then people think one is imagining things, but he said that you know your body, no-one else can say anything else. It was good that someone understood the problem.” [“Han sa också att e finns bara en liten procent som får fram att di är mögel allergiker för majoriteten e bara superkänslig och he e ju probleme me hanje trovärdigheten, eftersom folk tro att man inbillar sej, men han sa att du känner din kropp, ingen annan behöver säg nå annat. Va ju bra att nån fatta probleme.”]*



When the informants are taken seriously they feel that they get affirmation of their health issue but also that what they feel is not something imaginary but something real.

### 11.3 The Struggle and the Outcome

The informants feel that their expectations of health care professionals and employers have not always been met and in order to get anything moving they had to be forceful themselves. Both informants feel that it has been a struggle to get their health issues recognized and a battle to get their needs met. Theme three discusses the vulnerability you feel as a patient when you reach out to health care and how dependent you are on health care in order to get your health issues recognized. This recognition can result in getting the right treatment.

In theme three the following categories emerge: **To be forced to do things yourself/rely on yourself, lack of trust** and **descriptions of giving up and moving on**. Theme three focuses on how the participants feel that due to their personality and fighting spirit they find inner strength to stand up for themselves and keep fighting. Theme three also describes how their battle comes to an end and what the outcome has been. Throughout the struggle their trust in employers and health care professionals has vanished.

#### 11.3.1 To be Forced to Do Things Yourself/Rely on Yourself

Both informants feel that in order for anything to happen they had to fight for themselves and find information themselves. They feel that if they had not been difficult, nothing would have been resolved and they would have gained nothing. Both informants think that it has been a struggle to get their health issues taken seriously and get any changes in place.

*“Well, I have had to do it all by myself. Although I pushed for them [meaning both employer and occupational health services] to do it, nothing happens.” [“Nå, man har fått dra dehe lasse själv. Ändå då man har påtryckt åt dem så händer int e na.”]*

It seems that even within health care the patient has to be forceful in order to be taken seriously and demand that certain investigations be made.

*“You never see anyone who has any understanding for the problems unless you handle them 100% by yourself and you have to make sure you get something out of it.” [“Man får aldri naen som har forståelsen for problemene om man int sköter dom ti 100% sjölv å man måst si till att man får ut naenting av e.”]*

It seems that personality traits play a large role in whether or not anything happens. If you are not a strong-minded person who trusts in yourself and your abilities you may not receive the adequate help and support from health care.

*“I am brought up to question yes, but not too strongly and not too much and one should have opinions, but not like you have to move forward like a steam roller because you feel like you have to fight. You have to tell them, 'hear what I am saying, you can think what you want but this is how it is'. One has to be very firm.” [“Så, ja e ju uppfostrad till att ifrågasätt jo, men int fö kraftit, int fö myki och man ska ha åsikter, men int så att man känner att man måst gå fram som en ångvält för man känner jo att man måst böre strid. Man måst ju sej till att 'hör nu va ja segär, så får ni tyck va ni vill men så je e'. Man måst va ganska bestämd.”]*

Both informants felt that they did not expect this struggle to take place. However, when they did not feel that they got the response they expected, they found inner strength to fight for their cause.

### **11.3.2 Lack of Trust**

The informants think that after all these years of fighting for their rights, they do not feel confidence in the health care system anymore. Since their needs have not been met they have finally come to the conclusion that you can only trust yourself and not others.

*“You have to be strong, and trust yourself, you have to because I have learned that you can't trust healthcare, if I would I wouldn't have had any type of specialized care today and god knows what they would have done to me, I just don't know. I can't speculate what could have been but I know many who aren't strong personalities and they go back and forth within health care and nothing gets done.” [“ Vari stark och lita på sig,*

*man måst ju för man kan int. Ja har ju lärt mej, e går int att tro på hälsovården, då sku ja int ha haft naen specialistvård ida och vetefan va di ha gjort me mej, ja vet int. Ja kan int spekuler va som ska händ om int. Ja känner ju mang som int e lika stark ti person, som far som ett jävla jehu fram och tibak in om vården och di far som fram å tibak å di får som int na gjort.”]*

When you are ill and seek care you are forced to trust others. However, both informants feel that after this experience they do not have the trust for health care nor for their employer anymore.

### 11.3.3 Descriptions of Giving Up and Moving On

The informants both feel that their fight came to a point when they gave up and had to move on. For one informant it took three years before he reached that point. He came to the conclusion that his fight was pointless and would not change anything anyway. He felt that he had to accept and move on; that although he feels that his expectations of his employer are not met, he cannot continue anymore. He has accepted and has now taken on other duties in a building that he knows will not give him any symptoms. He is not necessarily happy and satisfied with the outcome but he feels that the options given to him would be to quit his job, go back to school, continue on in the old facility that affected his health or the one he chose, which was to take on other duties.

*“Yes, they give me other duties. Although it didn’t result in what we originally had decided, but I just didn’t feel like I wanted to fight anymore.” [“Jo, di ger mig andra arbetsuppgifter. Men e blev ju int riktigt som vi kom överens om, men jag orka int börja bråk nå mer”]*

One informant says that throughout the years she has come to terms with it and accepted that she cannot work with what she always wanted to do and that at this point she is okay with it. She thinks that she needed all these years to get to the point of accepting and that it would have been much more heartbreaking for her if someone had told her in 2004 that she would never be able to work with children again. She also sees her personality as a factor that makes it easier for her to move on. She feels that she is the type of personality that would not be able

to work at the same place for longer periods of time anyway and that she likes to try new things. Even though things did not work out as she planned she is glad that she ended up doing what she is doing now instead.

*“Yes I think it has to do with my personality, I’m the type who could never work at the same place 30 years. I ... have to be able to try different things. Yes, maybe I should have been self-employed a long time ago, because I like to decide and be on top of things”. [“Ja tror no kanske att e har ti gör me min personlighet för att, ja e ju en sån att ja sku aldri kon job på ett ställ i 30 år. Att ... ja måst få prov på olika saker. Ja e, kanske egentligen sku borda ha vari egenföretagar för lang sedan, för ja, ja vill bestäm å ja vill ha koll på att e ska va som e ska va.”]*

Giving up has for one informant taken time but now she feels as if it is not necessarily something negative. Although she wishes she had not had this experience she has come to the conclusion that the outcome has led to something positive. The other informant has also accepted his faith and moved on and although he wished the outcome had been different he does not feel as if he wants to dwell on this any longer.

## **12. Interpretation of Results**

In this chapter I am interpreting the results of my interviews, through the theoretical framework of Eriksson and Bäckman but also by looking at previous research. In the first sub-chapter I interpret the results using theory and in the second sub-chapter I interpret the results in relation to previous research. I separated my interpretations of the results in order to clarify my interpretations for the reader. The use of theory when interpreting the results highlights certain aspects of the informants' lived stories, in this case suffering and health/perceived health. When I used previous research I wanted to draw on similarities found in previous research to particular symptoms and causes that were experienced by the two informants.

## 12.1 Interpretation of Results Related to Theories

In this chapter the results from the categories will be interpreted using Eriksson's theory about suffering and Bäckman's theory about health.

According to Bäckman there are four factors that affect an individual's health; these factors are biological, lifestyle, environmental and health systems (1991, p. 32, p. 37).

In the case of our informants, both of them have previous medical conditions that worsen due to exposure to components in a building. One informant's medical condition worsens due to tree dust and the other has both allergy and asthma that have become increasingly worse due to exposure. According to doctors, the multiple times she has been exposed to mold have caused her body to become increasingly weaker and develop new sensitivities and allergies as well. Therefore, having previous medical conditions is a biological factor that possibly increases the likelihood of getting symptoms that affect your health negatively. Both informants have also developed other newer symptoms that are not connected to their previous medical condition. One informant had higher blood pressure, tiredness, memory loss, headaches, runny nose and eyes. The other informant had also developed arrhythmia, itchy rash, tiredness and moodiness.

Their lifestyle has also been affected due to their health problems. One informant had to make radical changes in her life in order to improve her health. She had to leave her profession and something that she not only liked doing and always wanted to do but something she had earned a higher degree in. She was forced to find a job that she could do in an environment that does not affect her health negatively and therefore she started her own business and now works from her own home. This was a major lifestyle change. The other did not make such a radical change and is still working as a teacher. However, he had to leave the subjects that he enjoyed most and take on other subjects. Otherwise he would have had to get another profession or quit his job, alternatively be on prolonged sick-leave.

Also environmental factors have played a role in their health. According to one informant it is due to a faulty ventilation system that he has got symptoms. The other informant reacts to mold due to dampness in a building but also because of construction or renovation errors in a building which has resulted in mold. Later on she has also developed allergies to chemical

components such as formaldehyde and thus reacts to products that contain formaldehyde and also to people that use products containing formaldehyde. She has also developed sensitivity to moisture in nature caused by rain or snow.

Health system factors also have affected the informants' health. Both informants have experienced that their symptoms and perception of their own health are not always taken seriously by health care staff and employers. Since SBS is difficult to diagnose and since the cause often results in expensive sanitations of a building they both feel that the expectations they had of health care professionals and employers have not always been met. One informant feels that although his health is impacted negatively by his work environment it is discouraging that nothing is being done to resolve the issue. It is easier to put him on sick-leave and get a substitute teacher. The other informant feels that even though some places where she worked did sanitations of the buildings where she detected mold, the process was slow and she was forced to leave the building before the sanitation was done due to her failing health. She has often felt that others have not completely understood the seriousness of her deteriorating health and that at times they even suggested that it was her imagination or mental problems rather than physical. Both informants feel that health care personnel are too overworked to really look into their health issues further and they also feel that unless a doctor is an expert and has knowledge about SBS they are not being understood and taken seriously.

According to Bäckman, a patient's perception of their own health should be included when diagnosing disease (1991, pp. 13-14). Both informants have had negative and positive experiences. They feel that their own perception of health has not always been taken to account or thoroughly investigated. However, when they have seen specialist doctors they have had a more positive experience. Then their own feeling about their body and health has been an important factor in their diagnosis and they feel that they have been taken seriously. In fact, one informant mentions that due to the difficulty in diagnosing SBS her own perception has been the determining factor in diagnosing. When she experienced arrhythmia they did a thorough health investigation based on her feelings and determined that it was not serious although uncomfortable. The doctors took her seriously and acknowledged how she felt, which is in itself to be recognized.

According to Bäckman, disease is affected by the social environment (1991, pp. 13-14). When the informants were not able to work and they have been on sick-leave, their social

environment has been affected. When one informant was working he was greatly affected by his symptoms and was not able to do anything productive after work, which also has affected his social environment. Bäckman regards quality of life as connected with health (1991, pp. 13-14). Both informants feel that their quality of life has been profoundly affected by the symptoms and their health issues. One of the informants has a hobby that brings a lot of joy to her life, however, due to her symptoms her ability to do her hobby is limited and this causes great sadness. Therefore her quality of life is affected negatively by her symptoms. She also feels that she is much more limited to what she can do since she reacts strongly to products containing formaldehyde, to humidity in nature and mold, and no longer has the carefree life she used to prior to 2001 when her symptoms got increasingly worse. Her quality of life is no longer what it used to be but she remains positive and tries to find other ways of living a good life. Acceptance and a positive attitude play a large role in her ability to make the best out of her current situation. Support from others is also crucial in order to keep fighting for your rights and in times of doubt be reassured that what you are feeling is real and visible to others.

According to Eriksson, suffering can be caused when an individual does not feel that they are taken seriously. When someone feels that their needs are not being met and they are not seen it can cause suffering. She also argues that human dignity lies in one's credibility. If others doubt or question you it violates your dignity and causes suffering (1994, p. 23, p. 27, p. 42, p. 84). Both informants have experienced this type of suffering caused both by health care but also by employers. When they approached their employers they did not feel that what they were experiencing was taken seriously, nor were their concerns investigated. Their credibility was questioned and their dignity took a hit.

Also, Eriksson claims that when someone approaches health care with symptoms that are well defined and a diagnosis is clear, they receive the right care. However, if health care professionals fail to diagnose you, which has been the case with both informants, it results in a feeling among the informants that your symptoms are not "real" but instead psychosomatic (1994, p. 44). One informant even experienced that a doctor suggested that her symptoms were mental instead of physical and that she should see a psychologist.

A diagnosis is a way of getting recognized and believed. If the health care system does not recognize your symptoms, your credibility is questioned which can cause, shame, guilt, anger, and sadness. Not being recognized degrades you as a person and your entire being and identity

is affected, according to Eriksson (1994, p. 23, p. 42, p. 44). Both informants have experienced feelings of anger, bitterness, sadness, disappointment and even a feeling of being broken down when those who should care do not seem to care.

Eriksson reasons that if adequate care is not given or if no care at all is given to a patient, this causes suffering. She highlights in her theory about suffering the following causes of suffering due to health care: Violation of the Patient's Dignity, Condemnation and Punishment, Assertion of Power, Omitted Caring or Non-Caring (2006, pp. 79-85). I want to apply these causes to be a reaction due to the response of an employer as well as of health care staff.

Both informants have felt that their dignity was violated when health care professionals or their employer doubted or questioned them. One informant felt that when he had a concrete symptom due to his back he received accurate care, but when he expressed his symptoms due to issues with the room he is teaching in, nothing was done. The other informant felt that some doctors and other health care personnel did not recognize her symptoms or did nothing to thoroughly investigate them. She also experienced that a doctor questioned her symptoms but also her as a person; that her credibility was questioned and thus her dignity was violated.

It seems that the lack of response is a form of condemnation of your symptoms. When health care professionals or employers fail to respond according to expectations, the informants are punished. This lack of responsiveness results in an ongoing battle to get their needs met and changes to take place. When nothing happens their health issues are ongoing and particularly one informant's health has deteriorated significantly due to the lack of response from employers. One informant has repeatedly requested certain subjects instead of teaching in a room that affects his health negatively but his employer's lack of communication and lack of taking his requests into account can be seen as a form of punishment, as well as a form of assertion of power. It is also significant to point out that both informants feel that the choices given are to be on sick-leave for prolonged periods of time, work and feel that your quality of life is deteriorating at the same pace as your health, or quit your job and do something else. It is as if you as the patient are being punished for the symptoms that you are experiencing. If the employer does what is expected in situations with SBS it takes a long time for something to happen and both informants feel that it is almost as if the employer waits for them to give up. This could also be seen as a form of not caring to resolve the issue. The same goes when one informant feels that there was no interest in compromising on behalf of the employer, nor did



the employer pay attention to what subjects he wished to teach. He had to take what they offered since the other options were worse. Also, due to the overwhelmed health care system both of them feel that there is a lack of sincere and genuine care, but they both seem to believe that it is because nurses and doctors are over-worked and see too many patients, with the result that they do not always have the time and energy to care about the individual patient. One informant said that she thought it strange that after all these years no-one cared to investigate her health and increased use of medication unless she pushed for it herself.

Suffering can, however, be the trigger to change in a person. This is the idea that out of something bad comes something good. Change does not necessary have to be that something better happens but it can also simply be just coming to terms with and accepting one's destiny (Eriksson, 1994, p. 48). Both informants feel that they have come to terms with and accepted their destiny. One informant feels that the lack of response from his employer ultimately led him to give up and take what they offered him, that is, other classes that the school administration chose for him. He feels that of all the choices that was the least bad one; however, he would have liked to see a different outcome. Still, he does not feel that he has the energy to continue but must accept and move on. For the other informant it took eleven years to finally come to terms with and not only accept that her health now is chronically poor due to all the many exposures, but she also had to come to terms with leaving her profession, which she enjoyed. She claims that due to her positive personality she has moved on and accepted and found something else to do that she feels she should possibly have done a long time ago. In her case she also experienced times when she was in doubt and was not even sure about her health herself, but through the support of family, friends, co-workers and others in the same situation she was able to finally accept her situation and move on.

According to Frankl there are several different stages of transformation when one suffers. The stage of creation is the trigger to action, the stage of experience is the emotional trigger, or hope, love and positive outlook, and the stage of adjustment is the change of attitude and coming to terms with the past and the new. Through these stages one can accept and the suffering is no longer suffocating the individual. By support and care from others it is easier to go through these stages and transform and get a new perspective on things (1990, p. 132). When one informant's health was negatively impacted by the building she was working in she was driven to action, which she claims also has to do with her personality. Both informants

seem to feel that when their expectations of health care professionals and employers are not met, they find some inner strength to stand up for themselves and claim their right. Through the suffering that is brought on by illness their certainty about what they are entitled to keeps them fighting for their rights. One informant grants her driven and positive outlook as the reason why she kept fighting for her rights. She also seems to have found support from others and joy in her life due to interests. The fact that her fight brought improvement for others as well seems to also be something that has given her great satisfaction and ultimately the ability to come to terms with the past and move on to the future.

## **12.2 Interpretation of Results Related to Previous Research**

According to Glas, one of the problems with SBS is that it is not easy to diagnose nor is there a common description and definition (2010, p. 14). The informants feel that part of the problem has been that their symptoms have been seen as a result of something else such as an existing medical condition although they were both certain early on regarding what caused their symptoms. They feel that since a common description of building-related health issues is lacking it has been a struggle getting the right diagnosis and treatment. The informants have also felt that their symptoms have not always been taken seriously by health care professionals and employers. The informants feel that their symptoms sometimes have been viewed as psychosomatic and the feeling of being misunderstood takes a toll on the participants' mental wellbeing. Lyles et al. have in their research come to a similar conclusion as the participants in this study. Those who are affected by SBS often feel that their symptoms are not taken seriously and that they are misunderstood by others. This causes a feeling of hopelessness and has an emotional impact on the person affected by SBS (Lyles et al., 1991, p. 68).

Both of the informants knew early on that components in a building/room affected their health negatively. One of the current ways of diagnosing SBS is seeing that others may be affected as well (Glas et al., 2008, pp. 1297-1303). This was the case with both informants. Co-workers also showed signs of SBS-related symptoms. Another factor is that once the individuals remove themselves from the building/room their symptoms improve and when they return the symptoms resurface (Glas et al., 2008, pp. 1297-1303). This is something that both informants

noticed. When on vacation or sick-leave their health improved significantly, but when they returned to work the symptoms came back with renewed strength. The argument among scholars has been the importance and effect already existing medical conditions may have on an individual's perceived symptoms and whether or not this is SBS-related. The reasoning has been that already existing medical conditions may be confused as being caused by SBS. However, many argue that certain already diagnosed medical conditions do indeed worsen due to building-related flaws (Glas, 2010, p. 15; Norrbäck, 2009, pp. 55-58). Glas' research for instance has shown that if you have asthma you are more likely to develop symptoms due to SBS (2010, p. 15). In the case of the informants, both of them did have already existing medical conditions, one with a lung disease and the other with asthma and allergy, but neither of them felt that their medical condition had affected their lives in any major negative way prior to exposure. Also symptoms not related to the already existing conditions surfaced once they were exposed. Typical symptoms of SBS are mucous membrane symptoms, dermatological symptoms and respiratory symptoms but also symptoms affecting the nervous system such as headaches, concentration difficulties, dizziness, fatigue etc. (Glas, 2010, p. 12). One informant's health was affected by the tree dust that accumulated in one of the classrooms due to a faulty ventilation system. His medical condition worsened and he did indeed have more difficulty breathing. However, he also had problems with his eyes, tiredness, fatigue and even increased blood pressure. Several researchers have come to the same conclusion that if pollutants build up in a room due to poor air flow and ventilation it can result in symptoms such as skin problems and mucous membrane problems but also fatigue and tiredness (Heimlich, 2007, p. 1; Burge, 2004, p. 187; Seppänen et al., 2004, p. 103). The other informant was mainly affected by mold and dampness. Norrbäck, (2009, pp. 55-58) Seppänen et al. (2004, p. 108) and Glas (2010, p. 19) have found in their research connections with upper respiratory symptoms due to mold and dampness. The informant's asthma in combination with both mold and dampness caused her symptoms to worsen, making her unable to work.

Considering how many schools seem to be affected with problems with indoor air quality and mold and dampness, it is disturbing to know that exposure to things that cause SBS for prolonged periods of time during childhood and adolescence can result in chronic illnesses and life-long health issues (Salo et al., 2009, pp. 185-194). Studies made in Sweden have also come to the conclusion that symptoms can become chronic due to prolonged exposure (Norrbäck, 2009, pp. 55-58). Children are also, according to some researchers, the most

vulnerable to the effects of allergens (Seppänen et al., 2004, pp. 102-115). One informant was even able to pinpoint how her exposure to mold when she was 13 caused the sensitivity that doctors say is the reason that her health immediately reacted when she was older, which ultimately led her to chronic illness that affects her quality of life and her ability to live a normal life and have a regular job.

## **13. Critical Review**

In my critical review, I have used Bickman's book about how to design a qualitative study and also Larsson's criteria for how to perform a critical review of a qualitative study. I focus on the following criteria mentioned by Larsson: Perspective awareness, internal logic and quality of results. I also use Bickman's discussion on how to use existing theory and research.

### **13.1 Existing Theory and Research**

Using existing theory helps you organize your research. Theory enables the researcher to highlight their findings and make them visible to others.

The researcher can use theory as a tool to make connections between different sets of data. This connection makes it easier for the researcher to see phenomena or events that otherwise could have been overlooked or not understood (Bickman et al., 1998, pp. 78-79).

Through the use of theory I am able to highlight certain aspects of the participants' stories, making them clear for others to see.

Researchers have to be observant in order to not to be influenced by other researchers' assumptions of the subject they are studying. It is also important for researchers to make sure that already existing research does not influence the mindset of the researcher (Bickman et al., 1998, pp. 78-79).

I have chosen not to read research that focuses on similar stories aiming at describing the lived experience of SBS, in order not to be influenced and let such research frame my thinking and my study.

### 13.2 Perspective Awareness

According to Larsson, the researcher's pre-understanding influences the study. As we learn more our pre-understanding changes. The pre-understanding is what starts our journey of interpretation. The researcher needs to clarify and be aware of his or her pre-understanding and this awareness is part of the quality criteria of the research. Pre-understanding can have its basis in lived experiences, literature review but also the way we use theory as a form of interpretation (Larsson, 1994, pp. 165-166).

I did not know much on the subject of SBS prior to starting my research. I did read quite a bit of material to be well prepared in understanding the background of SBS, its causes and symptoms. However, I was careful not to read studies that focused on the subjective experiences of living with SBS and other life stories so that previous research would not affect how I entered the interview situation or how I interpreted the results. I did not want already existing material to influence or frame my research since my research is based on these individuals' subjective experience and no other studies. I chose to use Bäckman's theory of health since I find it applicable on how my informants perceived their health and what influenced their health and the perception of it. I also opted to use Katie Eriksson's theory about suffering to give my study a different theoretical approach.

### 13.3 Internal Logic

Internal logic is described as the point when all aspects of one's research come together and are in balance with each other. The research questions, the data collection, the technique of analyzing the material and the method used all blend together and are connected to each other. In the end of the research the discussion re-connects to both previous research and the aim or purpose of the study, making the research whole and part of a closed system. It is also obvious

what the researcher contributes to the study. The reader can follow the arguments and the research “makes sense” (Larsson, 1994, pp. 169-170).

The purpose of this study was to highlight two personal subjective experiences with SBS. In order for me to be better prepared for the interviews I read up on factors that cause SBS and symptoms. I also looked into what employers and occupational health services are expected to do when a worker's health is affected by SBS. This gave me the necessary pre-understanding to do the interviews and set the stage for a better understanding of the informants' experiences. Since this was a phenomenological study based on two people's experiences with SBS, I used in-depth interviews to collect data. The transcribed data was then analyzed using meaning condensation in order to highlight themes and subsequent categories. Through the use of my theory I was able to interpret the results.

### 13.4 Quality of Results

According to Larsson, richness of content is central when doing a qualitative study. Richness of content is gained when the result blends together with both the structure of the research but also the selected theory. Richness of content is reached when the researcher is able to describe phenomena as truthfully and colorfully as possible and not let their own opinions affect the descriptions. Larsson argues that there is an ongoing battle between richness of content and the structure of the study. The structure should highlight the main core of the study and through interpretation the raw data is processed. There has to be a balance between the richness of content and the structure. The structure should not limit or interfere with the richness of content. The research needs to have a clear reasoning and purpose and the steps taken in the study should be well defined and easy to follow for the reader. The interpretation should have its basis in theory and the theory should derive from the characteristics of the study (Larsson, 1994, pp. 173-176).

Since I am doing a phenomenological study, the aim of my study was to describe the subjective experience of SBS. Therefore I did not limit the study to certain questions that I wanted to ask but rather let the themes emerge from the raw data. These themes became the foundation for categories that described the subjective experience of the individuals that were

interviewed. Throughout my study I wanted to give the reader the pre-understanding necessary in order to better understand the experiences that the informants have had. By offering direct quotes from the raw data, the reader will get a glimpse of their reality without my interpretation. In my interpretation I have clearly listed the themes that emerged throughout the interview and the categories that answer the aim of the study. I have described the choices I have made regarding the method used in my study but I have also described the theories used.

## 14. Discussion

This study is part of the TEMA project. I wanted to gain a better understanding of what it is to be affected by SBS and what things affect the quality of life among those affected by SBS. The TEMA project seeks to find comprehensive guidelines for health care professionals, employers and those involved with constructing buildings in order to avoid discrepancies that ultimately lead to those affected by SBS not getting accurate and timely care (TEMA project plan). The results of this study will give a personal insight into what battles those affected by SBS may go through and where our efforts should be focused when improving systems such as health care or information to employers and builders.

Workplaces and schools are places where adults and particularly children spend large amounts of time. It lies in everyone's interest to make sure that the buildings we use do not affect our health negatively and cause illnesses that can, at worst, become chronic. Children are also persons who cannot speak up for themselves and claim their rights and unfortunately they are also the ones most vulnerable to allergens. It should be the moral quest for all of society to make sure that they are not exposed to components that can have a negative impact on their health and that are due to a faulty building.

The informants' stories show that they both had similar experiences with employers and health care professionals. It appears that for the most part they were not able to get their needs met in a timely manner. It seems as if the employers, due to the costs of sanitation/renovation, hesitated in making the required changes. It appears that the current standpoint of some employers is to do nothing and wait for the employee to quit or just extend the sick-leave,

which, if true, is something that society needs to address. In the long run, prolonged sick-leave and children who grow up with chronic health issues will cost society more than taking care of the matter immediately when problems surface.

It appears that health care professionals, due to being over-worked, are not able to do in-depth investigations. Only if the health care professionals are specialized in illnesses such as asthma or allergy or if the health care personnel happen to have the knowledge necessary to see the connection between symptoms and SBS, investigations are done. It may not be possible to change the workload; however, one suggestion would be to give all health care professionals the training necessary to be able to find those patients whose symptoms could be related to SBS. Asking the right questions of the patient could be a starting point. The second step could be the communication between health care staff and employer in order to make sure that everyone is on the same page as to what needs to be done. Currently it seems that without accurate diagnosis the patient feels lost and feels that their symptoms are not taken seriously, causing unnecessary stress and suffering. If you do not have the right diagnosis it is also difficult to get your employer to take responsibility, which by law they are required to do.

Another interesting observation made is that support from others with similar conditions strengthens the individual suffering from SBS and gives them the motivation to continue with the battle against key players in their society. It also gives answers and support, making the individual feel less isolated. According to one informant there are many who suffer in silence and do not want to make a fuss about their condition or are not even sure to what their failing health is due. Some even feel that it is pointless to bring it up with health care staff and employers since nothing will be done anyway and there is still the stigma around SBS as being psychosomatic and not a “real” physical condition. However, according to one informant there is currently no national webpage similar to for instance those available to people affected by diabetes or heart diseases. Creating a webpage could also be a suggestion for recognizing SBS and those suffering, as well as giving them an opportunity to get answers and know their rights and what steps they should take next. It would also serve as a connecting point for those who feel isolated and lonely with their symptoms.

This study has merely scratched the surface of what it is to live with symptoms caused by SBS. Based on these two stories it shows that it is an unnecessary and time-consuming battle to get your needs met and to gain the respect and understanding from those that are crucial in



improving your health; employers and health care professionals. It also shows how much these symptoms actually affect your daily living and quality of life. Lastly, it shows that although costly, there are important things that can and should be done in order make sure that others, such as children, are not exposed to unhealthy components caused by a building; components that may cause life-long health issues and that in the end are much more costly to our society.

## References

Arbetskyddsförvaltningen.(2009).[Online][www.tyosuojelu.fi/se/mogelochfuktskador](http://www.tyosuojelu.fi/se/mogelochfuktskador)  
(retrieved 15.09.12)

Arbetsmiljöverket. (2009). *Arbetsplatsens utformning: arbetskyddsstyrelsens föreskrifter om arbetsplatsens utformning samt allmänna råd om tillämpningen av föreskrifterna*. Solna: arbetskyddsstyrelsen.

Bell, I., Baldwin, C., Russek, L., Schwartz, G., Hardin, E. (1998). Early life stress, Negative paternal relationships, and chemical intolerance in Middle aged women: support for a neural sensitization model. *Journal of women's health* 7, (9). 1135-1149

Bickman, L., Rog, D. (1998). *Handbook of Applied Social Research Methods*. USA: SAGE Publications Inc.

Brauer, C., Mikkelsen, S. (2010). The influence of individual and contextual psychosocial work factors on the perception of the indoor environment at work: a multilevel analysis. *International Arch Occupational Environmental Health*. 83 (6). 639-651

Bäckman, G. (1991). *Individ, närmiljö och hälsa*. Helsingfors: Utbildningsstyrelsen

Denscombe, M. (2009). *Forskning handboken för småskaliga forskningsprojekt inom samhällsvetenskaperna*. India: Replika Press Pvt Ltd

Eriksson, K. (1994). *Den lidande människan*. Arlöv: Berlings

Eriksson, K. (2006) *The Suffering Human Being*. Chicago: Nordic Studies Press

Glas, B. (2010). *Methodological aspects of unspecific building related symptoms research*. Umeå: Print & Media

Glas, B., Stenberg, B, Stenlund, H., Sunesson, A-L. (2008). A novel approach to evaluation of absorbents for sampling indoor volatile organic compounds associated with symptom reports. *Journal of Environmental Monitoring* (10). 1297-1303

Graneheim, U.H., Lundman, B.(2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* (24). 105-112.

Heimlich, J.E. (2007). [Online ] Sick Building Syndrome, Ohio State University Fact Sheet. <http://ohioline.osu.edu/cd-fact/pdf/0194.pdf> (retrieved 10.21.11)

Kvale, S. (2007). *Doing Interviews*. Wiltshire: the Cromwell Press Ltd

Larsson, S. (1994). Om kvalitetskriterier i kvalitativa studier. In: Starrin, B. &Svensson, P-G. (ed.) *Kvalitativ metod och vetenskapsteori*. Lund: Studentlitteratur

Laumbach, R., Kippen, H., Kelly-McNeil, K., Zhang, J., Zhang, L., Liroy, P., Ohman-Strickland, P., Gong, J., Kusnecov, A., Fiedler, N.(2011). *Sickness response symptoms among healthy volunteers after controlled exposures to diesel exhaust and psychological stress. Environmental Health Perspectives*. 119 (7). 945-950

Lyles, B.W., Greve, K.W., Baure, R. M., Ware, M. R., Schramke, C. J., Crouch, J., Hicks, A. (1991). *Sick Building Syndrome, Southern Medical Journal*. 84 (1)

Morse, J.M. (1991). *Qualitative Nursing Research: A Contemporary Dialogue*. Newbury Park, California: Sage Publications, Inc.

Norbäck, D. (2009). An update on sick building syndrome. *Allergy & Clinical Immunology*. 9 (1). 55-59

Patel, R., Davidson, B. (1994). *Forskningsmetodikens grunder, Att planera, genomföra och rapportera en undersökning*. Lund: Studentlitteratur.

Polit, D., Beck, C. (2012). *Nursing Research*. China: Wolters Kluwer Lippincott Williams & Wilkins

Salo, P., Sever, M., Zeldin, D. (2009). Indoor allergens in school and daycare environments, *NIH J Allergy & Clinical Immunology*. 124 (2)

Seppänen, O.A., Fisk, W.J. (2002). Association of ventilation system type with SBS symptoms in office workers. *Indoor Air* 12 (2). 98-113

Seppänen, O.A., Fisk, W.J. (2004). Summary of human responses to ventilation. *Indoor Air* 14. 102-118

Streubert, H.J., Carpenter, D.R. (1999). *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Philadelphia: Lippincott Williams & Wilkins.

Trost, J. (2009). *Kvalitativa Intervjuer*. Lund: Studentlitteratur.