The experience of living with sensory hyperreactivity (SHR) – Accessibility, financial security and social relationships

Anna Söderholm

Department of Health Sciences, Mid Sweden University.

Supervisor: Steven Nordin, Department of Psychology, Umeå University
Co-supervisor: Anna Söderberg, Department of Nursing, Umeå University
ABSTRACT

Purpose: The purpose of the present study was to illuminate how individuals living with SHR, experience its impact on accessibility, financial security and social relationships.
Method: A qualitative approach was used. The participants were recruited by advertising on the website for “The network for people with odor intolerance”. The data was collected by written descriptive texts from the participants and analysed with qualitative content analysis.
Results: The results showed that the informants experienced an extensive lack of accessibility in society. It was difficult to move around in society, to visit public buildings and facilities and it was almost impossible to find a suitable place to live. Regarding financial security they had a reduced income due to difficulties to earn their living in combination with increased expenses because of the disease and they had difficulties to get the support they needed from authorities. This created an insecure financial situation. Further, the findings showed that their social relationships had been affected. Socializing with others had become hard and troublesome, they had become limited in doing social activities and they got support from some but these persons became limited. Six themes permeated the categories in all three content areas: “Being limited”, “Being forced to behave incompatible with your true personality”, “Experiencing a lack of understanding and respect from others”, “Experiencing insecurity”, “Being dependent on others” and “Being forced to choose between the plague and cholera”.

Keywords
Sensory hyperreactivity (SHR), Multiple chemical sensitivity (MCS), odor intolerance, disability, accessibility, health determinants
SAMMANFATTNING

Syfte: Syftet med denna studie var att belysa hur individer som lever med sensorisk hyperreaktivitet (SHR) upplever dess påverkan på tillgänglighet, ekonomisk trygghet och sociala relationer.

Metod: Kvalitativ metod användes och deltagarna rekryterades via Internet genom annonsering på nätverket för doftöverkänsligas hemsida. Datainsamlingen skedde genom skrivna berättelser från deltagarna och data analyserades sedan med kvalitativ innehållsanalyss.

Resultat: Resultatet visade att informanterna upplevde en omfattande brist på tillgänglighet i samhället. Det var svårt att röra sig i samhället, att besöka offentliga lokaler och inrättningar samt att det var nästan omöjligt att hitta en lämplig bostad. Deras ekonomiska trygghet var påverkad genom att de hade minskad inkomst på grund av svårigheter att försörja sig i kombination med ökade utgifter orsakade av sjukdomen samt att de hade svårigheter att få det stöd de behövde från myndigheter. Detta skapade en otrygg ekonomisk situation. Deras sociala relationer hade blivit påverkade av sjukdomen. Att umgås med andra hade blivit jobbigt och besvärligt, deras sociala aktiviteter hade blivit begränsade och de fick stöd av vissa men dessa personer blev då begränsade. Sex teman genomsyrade kategorierna i alla tre innehållsområdena: "Vara begränsad", "Vara tvungen att bete sig oförenligt med sin rätta personlighet", "Uppleva brist på förståelse och respekt från andra", "Uppleva otrygghet", "Vara beroende av andra" och "Vara tvungen att välja mellan pest eller kolera".

Nyckelord
Sensorisk hyperreaktivitet (SHR), Multiple chemical sensitivity (MCS), doftöverkänslighet, funktionshinder, tillgänglighet, hälsans bestämningsfaktorer
Intolerance to odorous and pungent substances is a frequently reported problem in industrialized countries. Odor intolerance and odor sensitivity are both terms used for self reported problems related to exposure to odorous and pungent substances. Odor intolerance is about twice as common in women than in men (Johansson, 2008). Another term that odor intolerance often is used synonymously with is chemical sensitivity. But chemical sensitivity is a wider concept that includes self reported problems related to exposure to non-toxic concentration of chemicals which could be either odorous or non-odorous (Johansson, 2008).

In 1987 Cullen described a condition called multiple chemical sensitivity (MCS) which is defined as “an acquired disorder characterized by recurrent symptoms referable to multiple organ systems. These symptoms occur in response to demonstrable exposure to chemically unrelated compounds at doses far below those known to cause harmful effects in the general population. No single widely accepted test of physiological function has been shown to correlate with symptoms” (Cullen, 1987).

Common symptoms for individuals with MCS are headache, dizziness, difficulties concentrating, muscle aches, stomach distress/nausea, burning eyes and astma like symptoms (Caress & Steinemann, 2003) and common triggers are pesticide, new carpets, car exhaust, perfume, cleaning agents, new furniture and fresh ink (Caress & Steinemann, 2003).

Other terms used for this condition is “20th century disease”, “environmental illness” (EI), “chemical hypersensitivity syndrome”, “total allergy syndrome”, “universal allergy”, “cerebral allergy”, and "idiopathic environmental intolerances" (IEI) (American Academy of Allergy, Asthma and Immunology Board of Directors, 1999).

MCS is a contested diagnosis and Das Munshi, Rubin and Wessely (2006, 2007) point out lack of biological tests that confirm its presence and a lack of objective provocation studies. There are different opinions among researchers whether MCS is caused by psychological (Staudenmeyer 2001) or physiological mechanisms (Caress & Steinmann, 2003, 2004). Reed Gibson and Lindberg (2007) make the comparison with multiple sclerosis, lupus and endometriosis, that from the start has been questioned as physiological but are now generally accepted as being truly physiological conditions.

The prevalence of MCS in the USA is 11.2 %, for self reported, and 2.5 % with a medical diagnose of MCS (Caress & Steinemann, 2004). In a survey in Germany with 2032 participants, 9 % reported chemical sensitivity and 2.5 % reported that they had been diagnosed with MCS by a physician (Hausteiner, Bornschein, Hansen, Zilker & Förstl, 2005).

A study with 4242 participants has been carried out to estimate prevalence and consequences of self-reported symptoms induced by airborne chemicals in a Danish general population. In this study, 1911 individuals (45% of total) reported annoyance induced by airborne chemicals, 1134 (27 % of total) reported annoyance due to symptoms and 777 (18 % of total) were only annoyed by the odor. Of these 1134 individuals with symptoms, 141 reported adjustments of social life or occupational conditions due to the symptoms (Berg, Linneborg, Dirksen & Elberling, 2008).

In Sweden, several studies have been carried out on individuals with upper and lower airway symptoms induced by odorous and pungent substances, such as perfume, cleaning agents, car exhaust fumes and cigarette smoke. These individuals have symptoms that resemble asthma and/or allergy but they show negative outcome on tests for asthma/allergy. Studies on these patients have led to a suggested explanation that the pathophysiology is related to increased sensitivity of free overactive nerve endings in the sensory nervous system in the airways (Johansson, Löwhagen, Millqvist & Bende, 2002; Johansson, Millqvist, Nordin and Bende, 2006; Millqvist, Bende and Löwhagen, 1998). A C-fiber hypersensitivity has been proposed (Millqvist et.al., 1998). Capsaicin, which is a pungent ingredient in red pepper is known to stimulate unmyelinated C-fibers of the sensory nervous system, therefore it has been used as inhalation provocation to test sensory hyperreactivity. These individuals with airway symptoms induced by odorous and pungent substances react significantly stronger to the capsaicin provocation test than do healthy people and patients with asthma. The condition is therefore called sensory hyperreactivity (SHR), (Johansson et al. 2002). Cough provocation with capsaicin has shown to be an objective way to test SHR.
A study by Millqvist, Ternesten-Hasseus, Ståhl and Bende (2005) shows a significant increase of nerve growth factor (NGF) in the nasal lavage fluid of individuals with SHR after capsaicin provocation, compared with healthy controls, which demonstrate a pathophysiology in the airways. Johansson et al. (2006) suggests that it should be called airway sensory hyperreactivity, pointing out the hyperreactivity of the sensory nerve system of the airways. According to Johansson, (2008) and Millqvist (2008) there are also individuals who have both asthma and SHR.

In studies by Nogami, Odajima, Shoji, Shimoda, and Nishima (2004) and by Ternesten-Hasséus, Bende and Millqvist (2002) the capsaicin provocation test has been used on individuals with MCS, and the findings from these studies show that individuals with MCS react significantly stronger to capsaicin than healthy controls. This could support a hypothesis of neurogenic mechanisms behind MCS and suggest a overlap with the condition SHR.

Common symptoms of SHR are heavy breathing, difficulties getting air, pressure over the chest, nasal blockage, coughing and eye irritation. Some also have more general symptoms such as headache and fatigue (Johansson et al. 2002; Johansson et al. 2006; Millqvist et al. 1998). Provocation with perfume, single-blinded in a placebo-controlled randomized study shows that individuals with SHR show symptoms induced by perfume even when they cannot smell the perfume. In this study the sense of smell was blocked by a nose clip and because the nose was blocked, only symptoms in the eyes and the lower airways could appear. The increase in symptoms during the 30 minutes exposure of perfume was significant compared with placebo (Millqvist, Bengtsson and Löwhagen, 1999).

To quantify self-reported affective reactions to and behavioral disruptions in daily life by odorous/pungent substances, for people with SHR, the Chemical Sensitivity Scale for Sensory Hyperreactivity (CCS-SHR) has been developed. In combination with other methods such as capsaicin provocation, it can be used to diagnose SHR (Nordin, Millqvist, Löwhagen & Bende, 2004). The prevalence of SHR has been estimated to be 6.3% in the Swedish general population with the diagnose criteria: positive capsaicin provocation test together with a CSS-SHR score >43 (Johansson et al., 2006).

A longitudinal study by Ternesten-Hasseus, Millqvist and Löwhagen (2007), in which the Nottingham Health Profile questionnaire was used, shows that individuals with SHR have reduced health related quality of life, with significantly higher scores for the domain social isolation and also significantly more problems in paid employment, housework, social life, hobbies and holidays, than a reference group.

One study of individuals with SHR, using qualitative approach has been published to this date. Larsson and Mårtensson (2009) describe experiences of limitations in life situations because of the adjustments they make to avoid substances that induce symptoms. They also experience a lack of understanding from other people and feel misunderstood in contact with health care. Further, one way for them to manage their symptoms is to disparage them (Larsson and Mårtensson (2009).

Because there are very few studies describing the life situation of individuals living with SHR, findings from studies on the resembling condition, MCS, may shed some light on this issue. Reed Gibson, Cheavens and Warren (1996) describe life disruption for individuals living with chemical injury (CI), EI or MCS. The study show that difficulties in work, finances, access to public spaces, housing, relationships and difficulties in getting help and being taken seriously by health professionals are common. So is also personal distress and for many of them even severe stress or trauma due to the life changes and losses caused by their condition (Reed Gibson et al. 1996). An etnographic study by Lipson (2001) shows three main ways of self-care for people living with MCS, prevention/avoidance, detoxification and emotional self-care. A qualitative study from Denmark of people with MCS having positive result on the CSS-SHR, by Skovbjerg, Broson, Rasmussen, Johansen and Elberling (2009) show that MCS can can have a severe impact on everyday life including lifestyle, social relations and occupational conditions. In another study about MCS by Reed Gibson and Vogel (2008) where the Sickness Impact Profile was used, the results show that the most serious dysfunction are in the categories of work, alertness behavior and
recreation and pastimes.

About one million people in Sweden in the ages 16 - 64 have an impairment (the Swedish term: "funktionsnedsättning"), and the most common impairments are motor-impairments and asthma, allergy and other hypersensitivity (The Swedish National Institute of Public Health (2008). The Swedish National Institute of Public Health uses The Swedish National Board of Health and Welfare’s definitions of impairment and disability: Impairment is a reduction of a physical, psychological or intellectual function that could appear as a result of disease or another condition, or in consequence of a innate or acquired injury, which can be of a permanent or temporary nature. Disability (the Swedish term: funktionshinder) is the limitation that the impairment leads to for the individual in relation to the environment. Examples of limitations are difficulties to manage daily life, lack of participation in working life, recreational and cultural activities, education, social relationships and democratic processes. Above all it is about lack of accessibility in the environment (The Swedish National Institute of Public Health, 2008). These definitions are used in the present study. The United Nations uses a resembling definition of disability: The convention on the rights of persons with disabilities 2006, acknowledge that disability is an evolving concept and the convention does not define it, but the treaty does state that: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (The United Nations, 2006, s 4). The convention emphasize that disability should be seen as the result of interaction between a person and her environment (The United Nations, 2006).

In 2003 the Swedish Parliament adopted a new public health policy with one overarching aim, to improve public health and reduce inequalities in health among different groups of the population, and eleven objective domains. In the objective domains, health determinants are used, which are factors in the structure of society, people’s living condition and lifestyles that effect health in a good or bad way. Domain number one in the public health policy is "Participation and influence in society" (The Swedish National Institute of Public Health, 2005).

Social participation/social support is a health determinant in this domain (The Swedish National Institute of Public Health, 2005). Social relationships can be at the society level, the organization level or the individual level, i.e. the relationships to the nearest persons such as friends, family and relatives (The Swedish government proposal, 2007/08:110). In the present study, social relationships is defined as social relationships at the individual level,

Accessibility is also a health determinant in domain number one, and it is a fundamental necessary condition for participation in the society (The Swedish National Institute of Public Health, 2005). The Convention on the rights of persons with disabilities, adopted by the United nations in 2006, emphasizes the importance of accessibility, which means that people with disabilities, on equal basis with others, should have access to buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces, and also to information, communications and other services including electronic services and emergency services (The United Nations, 2006).

According to the report “Onödig ohälsa” by The Swedish National Institute of Public Health (2008), reduced health/poor health is far more common then it needs to be among persons with impairments, and a large part of the illness in this group of people is related to known determinants, for example, lack of accessibility and financial insecurity, i.e. disability creating processes.

Financial security is a health determinant in domain number two in the public health policy: "Economic and social security" (The Swedish National Institute of Public Health 2005). The report from The Swedish National Institute of Public Health (2008) shows that people with disabilities have lower income and a lower cash-flow marginal then the majority of the population. It also shows that it can be expensive to have a disability because of for example, circumstances around transportation, housing accommodation or other things that increase the expenses. For the financial security it is important that they can get compensation for these expenses.

The Swedish National Institute of Public Health (2008) means that real efforts needs to be made to illuminate consequences on the health for people with disabilities.
The handicap research is well established but a large amount of the research is about analyzing what makes injuries and diseases become an impairment. Research about the interaction between individuals and society, especially what and which processes that hinder full participation, i.e. disability creating processes, is less developed. Therefore it is important to carry out research about this. There are also only a few impairments that dominate research, foremost motor impairments, intellectual impairments and to some extent vision impairments (The Swedish National Institute of Public Health (2008).

Since there is no effective treatment for SHR, individuals with SHR have to avoid exposure to odorous/pungent substances if they want to stay free of symptoms. This can be difficult in modern society with a steadily increasing use of chemicals and scented substances. To this date no study has been carried out that explores individuals’ experience of SHR with focus on health determinants and disability creating processes. Therefore the purpose of the present study was to illuminate how individuals living with SHR, experience its impact on accessibility, financial security and social relationships.

**METHOD**

**Methodological approach**

Qualitative approach is appropriate to use to answer research questions based on how, what and why (Fridlund & Hildingh, 2000). The individuals lifeworld is in focus in qualitative approach and the aim is to understand the informant from his/hers personal perspective and strive to get picture, as complete as possible of the informants situation (Olsson and Sörensen, 2001). According to Baum (2002) a qualitative approach in public health research is applicable to study economic, political, social, and cultural factors that influence health and disease in more depth than possible trough quantitative methods, and to gain understanding about how people interpret and make sense of their experiences of health and disease.

Considering the purpose of this study, a qualitative approach was therefore most appropriate to use in the present study.

**Data collection**

Written documents of different kinds from participants is a data collection method that can be used in qualitative research (Baum, 2002; Denscombe, 2007; Nygren and Blom, 2001; Olsson and Sörensen, 2001). Nygren & Blom (2001) suggest short reflective narratives as an alternative to interviews, where the respondents are asked to write down narratives instead of telling them orally and they get written questions and instructions for writing the narrative. According to Nygren and Blom (2001) one advantage with written narratives instead of narratives from an interview, is that the written narrative is more reflected and better understood by the respondent. The writer has time to reflect about his answers and go back and forward from the parts to the whole in the text which makes the narrative more reflective and better understood by the narrator. Another aspect is that the narrative written by the respondent is less controlled by other people than the writer. It is controlled only by the instructions given to the respondent. The method is also time saving compared to interviews since the time-consuming transcription of recorded interviews is left out (Nygren & Blom, 2001). However, limitations with this data collection method are that it requires that the respondents are adept at writing. Further, an interviewer could make the respondent talk about things that the respondent might not pay attention to when writing alone (Nygren & Blom 2001).

One data collection method suggested by Sveningsson, Lövheim and Bergquist (2003) and by Denscombe (2007) is to conduct an interview by e-mail. Advantages with interviewing by e-mail are that the respondent has more time to think about the questions before answering which can improve the quality of their answers (Denscombe, 2007; Sveningsson et al. 2003) and that the interviewer effect (the impact of the researcher on the respondent) is reduced (Denscombe, 2007). Disadvantages is that the researcher cannot perceive non-verbal communication that could be of importance for understanding the interviewee (Denscombe, 2007; Sveningsson et al. 2003) and one
can only reach people with access to Internet, and who can express themselves though writing (Sveningsson et al. 2003).

The data collection in the present study was inspired by Denscombe (2007); Nygren and Blom (2001) and Sveningsson et al. (2003). The participants got a letter (Appendix 1) by mail with written instructions and three open-ended questions. The participants were instructed to write a descriptive text about their experiences of 1. accessibility, 2. social relationships and 3. financial security. Being a layman it may be difficult to know exactly what these terms include. Therefore to make sure that all participants perceived these terms in the same way, there was an explanatory text following every question to define what was included. To be able to write an explanatory text that was easy to understand for the participants, the author read discussions and narratives on the website “The network for people with odor intolerance”, to find practical definitions that the participants could relate to. By having an explanatory text the questions given to the respondents may be likened by a semi-structured interview guide.

The mentioned positive aspects of written answers from respondents, together with the wide geographic distribution of the participants were reasons for choosing this method for the data collection. For ethical reasons mail was used instead of e-mail so the collected data could be anonymous. An alternative because of the widespread geographic distribution could have been telephone interviews but then one will not get the advantages with face to face interviews such as bodily expressions, but still have the disadvantages such as time-consuming transcriptions and that the respondents will have less time to reflect before answering the questions. As mentioned before, the respondents should preferably be adept at writing. In the present study this has been taken under consideration when choosing place of recruitment.

Materials
To describe the sample, a background questionnaire and the CCS-SHR were used (Appendix 1). The CSS-SHR has been developed to quantify self-reported affective reactions to, and behavioral disruptions in daily life by odorous/pungent substances, for people with SHR. CSS-SHR has good test-retest reliability ($r_{xy} = 0.87$), good predictive validity, satisfying internal consistency ($r_x = 0.76-0.84$) and concurrent validity. The cut off score for SHR is >43. In combination with other methods such as capsaicinprovocation, it can be used to diagnose SHR (Nordin et. al. 2004).

Participants and procedure
The participants were recruited through the Internet by advertising on the website for “The network for people with odor intolerance”. At this website people with odor intolerance share their experiences of everyday life through written narratives and discussions at the forum. Therefore we expected to find participants with the diagnosis of SHR there, which were adept at writing and willing to write about their experiences of living with SHR. The inclusion criteria were being diagnosed with SHR based on capsaicinprovocation test, >18 years old and living in Sweden.

Sixteen individuals reported interest to participate. Twelve of them fulfilled the inclusion criteria and were therefore sent a letter of information and a form for written consent to participate in the study. Twelve individuals is an appropriate number of participants for this type of study.

In qualitative research, a large amount of material can make it difficult for the researcher to get a thorough knowledge of the material and it might result in a superficial analysis. Transcripts or text material from approximately fifteen participants is sufficient (Malterud, 2001).

Of these twelve individuals, all agreed to participate by signing and returning the written consent. A letter with instructions, background questionnaires and questions about their experiences was sent by mail to these twelve individuals. The participants were instructed to answer the questionnaires and to write about their experiences in a descriptive text and then return it anonymously by mail in an envelope with prepaid postage. All twelve individuals answered the questionnaires, wrote the descriptive texts and returned this. All of the participants had a CSS-SHR-score >43. The mean score of the participants in this study were 52.25 with the range between 44 – 55. Mean score in the Swedish general population is 34.8 (Johansson, Brămerson, Millqvist,
All twelve participants were women, which probably was due to the fact that SHR is overrepresented in women. Three of the participants had allergic asthma and one had furred animal allergy. Two participants had pollen allergy, one had fibromyalgia and another had migraine. Two participants had celiac disease and one of them also had lactose intolerance. The participants were aged between 23 and 64. The mean age was 47. Eight of them lived with a husband/partner, of these, three had children living at home. Of the four not living with a husband/partner, three of them lived alone and one lived with a cohabitant. All of the participants were non-smokers. Two of them had senior high school education and ten of them had university education. Three participants had sickness pension, four were sick-listed, one worked part-time and was part-time sick listed. One participant was part-time sick listed and in search of work part-time, one worked full-time and one was a full-time student. For six of the participants the onset of symptoms induced by odorous and pungent substances were related to previous long-term exposure to chemicals. For two of the participants the onset of symptoms were between the age 10-20 years, for one participants it was between the age 20-30 years, for three of them it was between the age 30-40 years and for six of them it was between the age 40-50 years.

**Data analysis**

Data analysis was conducted by using qualitative content analysis. Content analysis was developed in communication science (Mayring, 2000), and was initially used to deal with quantitative and systematic description of the content of communication. Over the time it has been developed to be used as qualitative content analysis in qualitative research (Graneheim & Lundman, 2004; Mayring, 2000). This analytic method was chosen because it is a well established scientific method for analyzing qualitative data, it is appropriate to use when the purpose is to describe or illuminate and it is also appropriate to use on written documents. In the present study qualitative content analysis has been conducted guided by Graneheim and Lundman (2004).

First, all the texts written by the participants were read through by the author and the co-supervisor to obtain a sense of the whole. Then the text from each participant were labeled with a letter from A-L, to make it possible to return to the whole text during the analytic process. The texts were scanned in to Word-documents to be able to perform the next four steps of the analysis more effectively by using the computer. In the first step the text was sorted into three content areas, accessibility, financial security and social relationships. Parts of the texts that did not relate to the research question were excluded. Some sentences where the meaning was too uncertain were also excluded to avoid misinterpretation. In step two the texts of each content area were divided into meaning units (sentences and words that relate to the same central meaning). The third step, to condense the meaning units, was in most cases not necessary, because the written text from the participants was already very condensed. Then in the fourth step, the meaning units were abstracted and labeled with a code. This was documented in tables of meaning units and codes, where the labels A-L made it possible to see which text-part came from which participant. The co-supervisor approved the meaning units and codes for each content area before continuing with the analysis. When all content areas were coded, the tables with the meaning units and codes were printed out and then the codes were cut out so the codes could be sorted manually. The codes were compared regarding similarities and differences and sorted into subcategories and then categories and main categories, each content area separately. The categories were determined in consultation with the co-supervisor. The last step of the analysis was to identify themes permeating the categories in the content areas. The themes were then determined in consultation with the co-supervisor.

**Pre-understanding**

Within qualitative research it is especially important for the researcher to give an account for his/her pre-understanding, which is his/her experience within the research area (Olsson and Sörensen, 2001). The author has an education in the fields of nursing science, medical science, health
promotion and public health science, and has done some health promotion work for people with physical impairments and with mental impairments. The author has symptoms from the upper airways induced by foremost perfume, which is under medical investigation. Since the author has no diagnose yet, has normal CSS-SHR score (<43 ) and symptoms mainly arise by long term exposure, it differs from the participants in this study, but still, the author has personal experience of the area. Efforts to minimize the effect of pre-understanding has been done overall by keeping aware of her pre-understanding throughout the entire research process, and specifically in choice of data collection method and work strategy in the analytic procedure. Choosing written narratives from the participants instead of interviews minimize the researcher’s effect on the respondent. In the analytic process the author has kept the analysis close to the text and after every step in the process the co-supervisor has checked and approved it before continuing with the next step.

Ethical considerations
This study has been designed according to the ethical guidelines of “Vetenskapsrådet” (http://www.vr.se/huvudmeny/etikforforskare/publikationerochriktlinjer.4.2d2de24108bef1d4a8800063.html). The participants got thorough written information about the study before signing a written consent to participate. For those who needed it, information was also available by telephone. The written consents were returned by mail separately from the questionnaires and the descriptive texts, which made the collected data anonymous. No specific risks of participating in this study was identified. The Research Ethics Committee of Mid Sweden University reviewed the study (20090401) and raised no objections from an ethical point of view.

RESULTS

Accessibility
The findings from the content area accessibility resulted in three main categories with categories and subcategories in one category which are showed in table 1. The results showed that the informants experienced an extensive lack of accessibility in society. It was difficult to move around in society, to visit public buildings and facilities and it was almost impossible to find a suitable place to live. Some informants also described this in overarching terms. They described a feeling of being excluded from society and that the accessibility is non-existing for them. They also described that they chose to expose themselves to scents in society at times even though they got ill, trying to live as normal as possible. But they got limited because there are a lot of scents everywhere in society and they could not be constantly ill.

Moving around in society is difficult
The categories show that they experienced a lot of difficulties with transportation both in daily life and when going on holiday trips, which made it difficult for them to move around in society.

Public transportation is difficult to use
Public transportation, such as bus, train, air plane and ferry (where there are others passengers) was difficult to use because they got ill when being exposed to other passenger’s scents. Some described that it was most difficult to use in the morning and on weekends because of the passengers being more scented at these times. Some informants described that they tried to move around in the vehicle to get away from scented passengers, but this strategy was not possible when having a fixed seat, like on a train. One informant (age 25) narrated:

*I feel very limited in using this kind of transportation, especially on Fridays and Saturdays when many people are strongly scented. I can use these but I get ill from doing so. I am almost always forced to move around in the vehicle to try to escape scents and smell of smoke in clothes (of other passengers). Going by air plane is tough but I do so very rarely. I am often forced to use the ferry which is very tough since they sell tax free perfume there. Going by train is also tough since you have a fixed seat and often are forced to stand up if the seat you have been given does not work because of scents.*
Table 1. Main categories, categories and sub-categories regarding accessibility.

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<thead>
<tr>
<th>Main-categories</th>
<th>Categories</th>
<th>Sub-categories</th>
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<tr>
<td>Moving around in society is difficult</td>
<td>Public transportation is difficult to use</td>
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<td>Using one’s own car is the best alternative, but not affordable for everyone</td>
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<td>Moving around outdoors can sometimes become difficult</td>
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<td></td>
<td>Going on holiday trips is difficult</td>
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<td>Visiting public buildings and facilities is difficult</td>
<td>Workplaces and schools are difficult to be at</td>
<td>Getting ill at the workplace/school due to a lot of scents there</td>
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<td>Trying to find ways to work/study without getting too ill</td>
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<td>Lack of understanding and support from the employer</td>
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<td>Lack of understanding and respect from colleagues/fellow students</td>
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<td>Struggling to work as usual</td>
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<td>Being forced to resign employment or give up career</td>
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<td>Medical facilities are difficult to visit</td>
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<td></td>
<td>Shops are difficult to visit</td>
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<td>Places of entertainment/culture and dining are difficult to go to</td>
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<td>Gym/sport centres are difficult to use</td>
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<td>Public lavatories are difficult to use</td>
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<td></td>
<td>Spa/beauty parlour/hairdresser are difficult to go to</td>
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<tr>
<td>Finding a suitable place to live is almost impossible</td>
<td>There is no accessible housing specially made for people with SHR</td>
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<td>Living in an apartment causes many problems</td>
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<td>Scents from previous residents cause problems</td>
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One informant described that she used a mask with a carbon filter when using public transportation but the mask did not help enough so she could be forced to get off the vehicle before reaching the destination. Another informant described that she did not feel comfortable using a mask. Air planes were described as difficult to use both because of scents from other passengers in the plane and because of perfume and fuel at the airport. One informant narrated that she had chose a job closer to home instead of another because she got so ill that it affected her work capacity when she was forced to use public transportation every day. Overall most of the informants described that they could not use public transportation because they got too ill when using it. Some described that they only used it if it was absolutely necessary.

One of the informants narrated that she had applied for mobility service because she could not use transportation where there are other passengers without getting too ill. The application had been
turned down but she had appealed against it. Another informant who used mobility service described that the drivers are ordered to refrain from scents but it was not always obeyed. Therefore she could get ill when using it and it led to worry before trips. Odor from the windscreen washer or cleaning agents used in the car or could also cause symptoms.

**Using one’s own car is the best alternative, but not affordable for everyone**

Difficulties to use public transportation led to needing an own car. Some of the informants had bought a car or had it already, but some reported needing a car but they could not afford it. Using an own car was described as the best alternative for transportation. Some of them though, narrated that even so, there could be some problems with cars too. These problems were that new cars and used cars bought at car dealers are sprayed with perfume, new cars can smell strongly of chemicals, used cars can smell from previous owners and gasoline cars can be troublesome to tank because of the strong smell of gasoline.

**Moving around outdoors can sometimes become difficult**

Two of the informants narrated that they could sometimes also have difficulties to move around outdoors. Meeting scented people on the street or passing by ventilation from a laundry room could cause symptoms. One informant described that she had to plan her way to school to avoid going where there is a lot of people.

**Going on holiday trips is difficult**

Going on holiday trips was described as being difficult. They got ill from scents both when going to the destination (on air plane, train, bus etc.) and when staying at the hotel/youth hostel/hired cottage. Getting ill on the holiday trip could ruin the vacation narrated some of the informants. This made them very limited to travel which was sad both for themselves and their family. One informant (age 44) stated: “The holiday trips have become the major problem. I get very ill when travelling by air plane and staying at hotels, and this is sad because my husband loves to go on journeys”. At hotels they could book allergy rooms but they were not free of perfume. They described that getting a place to stay that was free of scents at the holiday was impossible. One hostel, placed in the Swedish mountains, was free of scents though, because it was run by the Asthma and Allergy Association. Even though they got ill, they still tried to go on some kinds of holiday trips, with good planning and trying to decrease exposure to scents as much as possible during the trip. But the outcome, how ill they would get, was uncertain. One of the informants described that she had tried to go on a trip and they hired a cabin but all the textiles in the cabin were scented from previous residents so she got very ill. She also narrated that this uncertainty made it difficult for her to dare doing things like going on trips and every failed attempt made it harder for her to dare to try again. Another informant reported that the uncertainty had led to her feeling that she could not spend too much money on trips when the outcome was so uncertain, but nowadays she did try to go on some trips despite the uncertainty.

**Visiting public buildings and facilities is difficult**

The categories show that the informants experienced difficulties to visit public buildings and facilities. The informants also described in overarching terms that they had difficulties to visit public buildings and facilities because of a lot of scents there made them ill. They could get ill for several days, and the scents from the surrounding could get stuck in the clothes which could lead to needing to wash the clothes after every visit to public buildings and facilities. Some of the informants also pointed out that smoking at entrées hindered their accessibility.

**Workplaces and schools are difficult to be at**

Getting ill at the workplace/school due to a lot of scents there. The informants described that there was a lot of scents at their workplace/school which made them ill. Scents from cleaning agents and air fresheners used there and scents from colleagues/fellow students or patients (at health care
facilities) caused symptoms. One informant (age 23) wrote:

_I cannot stay at school without getting symptoms. The main reason is that there are a lot of people at school who uses perfumed products. Furthermore, there is often very poor ventilation and it can smell in the rooms even when they are empty. Chairs with textiles are often full of scents and my clothes smell when I have been sitting on the chairs. If there are a lot of people in the rooms, the entire me smells when I get home so I must immediately take a shower and change clothes._

Their experience was that it was very difficult or impossible to find a workplace free of scents. One informant described that she had to go down to the basement when they cleaned the workplace because the cleaning agent smelled strongly, but in the basement there was a person working who had a strong perfume. She (age 41) stated: “I had to choose between the plague and cholera”

The informants narrated that they got symptoms when they got close to colleagues/fellow students. They therefore had difficulties being where there are a lot of people or going to lectures and participating in group work. One informant narrated that she felt secure that she could get a job with her education but since she got ill when she needed to be at the school too often she was worried about being able find a workplace where the employer and colleagues are willing to adjust to her.

_Trying to find ways to work/study without getting too ill._ They narrated that they tried to find solutions which made it possible for them to work or study. They tried to inform the colleagues/fellow students at the workplace/school about refraining from wearing strong scents. One narrated that she thought that it facilitated some to work in the afternoon when all the recently administered scents had worn off a bit. One informants had got an own office but there was still problems because scents from the corridor came in and there were scents at common spaces.

Working/studying from home as much as possible was one solution. But since they got ill even the day after or several days after they visited the school/workplace it was difficult and needed a strict planning or could even make it impossible. One of the informants who studied narrated that she got notes from the lectures so she could study most from home and she was permitted to do examines in a private room, but since the invigilators often wore perfumed products it could still be a problem. She tried to use a face mask at obligatory tasks at the school but it did not help enough. One of the informants (age 45) who had struggled a long time trying to find solutions to be able to work, but were now sick listed, stated: “All responsibility is today laid on the individual, there is a need for decisions from politicians about accommodations and support for us.”

_Lack of understanding and support from the employer._ They had experienced that it was difficult to get understanding from their employer. One informant narrated that she had offered the employer information from a physician but it was turned down so she felt like they did not even want to try to understand. Some also felt that the employer did not believe them. It was difficult to get workplace accommodation and if they got some accommodation it was often after a long struggle. One of the informants narrated that she had brought up the problem with the person responsible for handicap issues at her workplace but she was met with lack of knowledge and understanding and got no help. Some of the informants reported that they had been treated very badly by the employer and even been harassed. One informant (age 45) reported:

_I have been harassed by a manager who sprayed perfume at the workplace and who also felt assaulted because I did not want to quit (working there). She set an ultimatum that I would be transferred or else she would go on sick leave. So I was transferred to another workplace where there were more irritants. ...I have now been given notice to be fired in a replacement process because my employer has chosen to get rid of employees who are long term sick listed… (she is today sick listed)._”

_Lack of understanding and respect from colleagues/fellow students._ The colleagues/fellow students had difficulties to understand their problem and they also had difficulties understanding when they smelled perfume. The informants also described that they had experienced that colleagues/fellow students did not believe them and they ignored the information about scents that they delivered to them. This could lead to conflicts and that they felt left out of the community at
work/school. One informant (age 52) wrote:

Although I have informed at meetings and through posted signs at the entrances to my corridor, my “colleagues”(?) used perfumes, after shave and strongly scented products. Many of them openly showed that they thought that I exaggerated and that I had no right to impose on their integrity. I was even told that I should express myself so I did not hurt anyone. Even my closest colleagues (in the same little group) “forgot” that I got very ill when they perfumed themselves.

Further, the informants described that it felt hard to ask colleagues/fellow student to refrain from wearing scents and that it was a sensitive thing because of the invasion of others integrity. One informant narrated that she had tried to get help from the union but it was difficult because of the conflicting facts in the Occupational Safety and Health Act. Everyone should be able to be at their workplace but on the other hand no one could be forced to not wear scents at work.

Struggling to work as usual. The informants narrated that at first and during as long time as they could bare it they had tried to work as usual even though they got ill at the workplace. They worked slower because they were ill and were forced to constantly work overtime to catch up. One of the participants was still working as usual. She described that she most of the times felt that she wanted to work as usual and she also felt that she did not want to let down people who depended on her. She had no accommodation of her work situation because she wanted to live a normal life. But she (age 47) also narrated that at days when she is exposed to scents that make her ill it was tough:

When I am ill I work at approximately 5% of my usual 100% capacity. It is painful to feel so “lost” which leads to exerting myself enormously to still seem to be as usual. I think I manage quite well, no one has ever said that they have noticed anything. But I feel that I have to exert myself very much to manage my work these days which leads to me not being able to do much more then my work...

Being forced to resign employment or give up a career. Many of the informants had been forced to stop working because of the scents at their workplace and they had not been able to find another workplace free of scents. Therefore most of them were now sick listed or had sickness pension. One of them narrated that she had changed job and was now trying to work part time. They described that it felt tough and sad being forced to give up their job or career. One informant (age 64) stated: “Both the forced part-time sick-listing and the current sickness pension have been at times very depressing. I really loved my profession!”

Medical facilities are difficult to visit Visiting medical facilities (including dentists) was described as difficult because of scents there, for example from cleaning agents, scented health care personnel, other personal working there and also scented patients and flowers brought by relatives. One informant narrated that she had experienced that it smelled strongly even at an allergy clinic. Another informant narrated that it had been difficult for her to visit health care units and she had tried to affect it by putting up notes at her district healthcare centre, but now it was easier since the decision about health care free of scents in that county council. Some of the informants described that health care personal often smelled perfume or tobacco smoke and had a lack of understanding and knowledge about odour sensitivity. On the other hand some described that they thought that the health care personal did not smell so much and seemed to understand them, but other personal there and other patients smelled much though. One informant described that sometimes when she was worse she needed a private waiting room. Another informant reported that her visits to the physician needed to be carefully planned ahead and sometimes it took place outdoors.

Shops are difficult to visit Grocery stores, department stores and other kinds of shops were difficult to visit. The informants narrated that there are a lot of scents there from scented products like hygiene-, washing- and cleaning- products, scented candles, flowers and scents from staff and other customers. One of the
informants reported that she often got problems at carpet and textile departments. One informant also narrated that she had experienced that staff smoked behind the refrigerator counters, which caused more problems. They narrated that they chose to shop groceries in the stores with the fewest scents and with decent ventilation. Placing of different products in the stores could cause difficulties. If scented products were placed were they could not avoid going, it was problematic, for example, placing of washing and hygiene products at the entrances and exits. Further the placing of non perfumed products among the perfumed products made it impossible for them to shop the non perfumed products without getting ill. One informant (age 52) wrote:

I have limited my grocery shopping to a big shopping mall where there is a wide space between the shelves, the ceiling is high and decent ventilation. There I can move away when I meet perfumed (or fabric softener-scented etc.) people. One big problem is that hygiene products often are placed at entrances or checkout counters. Unscented products are always interspersed between all the horrible perfumed products. If I pick up my shampoo myself I run the risk of getting ill. ...In most public spaces and shopping centres there are interspersed, strongly scented areas, for example shops like Kicks.

In department stores/shopping malls they thought that it was a pity that the perfume department or perfume store often is placed so it needs to be passed to get to other departments/shops. Some of the participants described that they used a face mask with carbon filter when shopping both groceries and other things. But some described that did not help enough. They could be forced to leave the stores before finished shopping. Some of the informants got help from a friend or their husband with shopping when necessary. One informant who had no one who could help her narrated that she could sometimes be laying at home ill with no food. She had tried to get help from the home help service in the municipality with grocery shopping but it was declined. She wrote that she had experienced a great treatment and some help from her local store though. Other difficulties that they mentioned with shopping were that many things like furniture, bags, clothes etc. are scented.

Places of entertainment/culture and dining are difficult to go to
The informants described that they got ill when they visited theaters, cinemas, concerts and lectures because they had to sit close to other people with scents. These activities were therefore avoided or limited to being very seldom. Some of them narrated that they tried facilitating it a bit by placing themselves aside and close to an exit. One of the informants narrated that she felt that she could not to spend too much money on tickets to cinema/theater/concert or fees for courses because she could be forced to leave right in the middle if she got too ill by other people’s scents. The informants described that they thought that their leisure activities had become very limited. One of them narrated that she had adjusted her interests because of her condition to doing activities at home or outdoors instead. Another informant (44) stated: “I go to the theater, cinema and restaurant a few times a year and then one must pay the price... one has to allow oneself certain things despite all.”

Going to restaurants/bars or cafés was also difficult because they got ill of scents on other guests, personal, air fresheners or tobacco smoke from the entrée. Strong spices could also cause symptoms at restaurants. The smoking prohibition had facilitated restaurant visits a bit though. Sitting at an outdoor café could facilitate but then the smoke became a problem, and if someone had a very strong perfume it did not help to sit outside. Some informants described that they could be forced to leave the restaurant in the middle of a meal. One informant (age 53) wrote:

Restaurants/cafés are almost out of the question. Sometimes I try but I am often forced to leave my food because someone who smells comes in... In the summer it is easier but today many (people) are so strongly perfumed that it does not help to sit outside, I get ill anyway. The worst thing besides strong perfume (perfume applied to the skin) is the smell of laundry detergent/fabric softener. These products are today “awfully” perfumed.

Gym/sport centres are difficult to use
Gym and sport centres were described as difficult or impossible to use due to scented people there and a lot of perfume from scented products that are being used there. At swimming baths they got symptoms both from the chlorine and from other peoples’ scents. Some of them tried to be able to
exercise by going there at times when there are less people there. Others were walking and trying to exercise at home instead. One of the informants (age 23) described her difficulties to find somewhere to exercise indoors:

This winter I tried to find somewhere to exercise indoors. Because it is not possible (for me) to train at an ordinary gym I got in contact with a physiotherapist through the district health care centre. Through her I tested exercising at a rehab gym. It went well once when I was the only one there. The following times it did not go well, since there were people there who smelled perfume. I simply had to give up and realize that it did not work. Then I borrowed the gym in our condominium but I could not be there either because of mould in the hall so I coughed as soon as I entered.

Public lavatories are difficult to use
The informants described that public lavatories are so strongly perfumed that they cannot use them without getting ill. Therefore they avoided using public lavatories. If they had to use them they got ill and they could not use the soap there because it is perfumed.

Spa/beauty parlours/hairdressers are difficult to go to
Visiting hairdressers was experienced as difficult because there was impossible to find a hairdresser free of scents, but they tried to make it as good as possible by going first in the morning and having the door open. Going to a beauty parlour or a spa was described as impossible.

Finding a suitable place to live is almost impossible
The categories show that it was difficult or impossible for them to find a suitable place to live. Some of the informants also expressed this in overarching terms, describing that it had been difficult, very difficult or impossible to find a suitable place to live.

There is no accessible housing made specifically for people with SHR
One of the informants lived in an apartment in a housing area accommodated for people with allergies. She (age 61) stated:

Since 15 years now I live in the only housing in the community that is accommodated for people with allergies. In this housing area smoking and furred animals are prohibited. There are no plastic materials in the apartments. There are central vacuum cleaners in every apartment. Unfortunately they missed prohibiting perfume.

Another informant described that she had not got any help from authorities with housing and she points out that she thinks that special housing needs to be built. She narrated that she is willing to move anywhere if she could get a home where she can stay well.

Living in an apartment causes many problems
The informants described that living in an apartment was difficult because there were so many factors there that made them ill. Scents and tobacco smoke from neighbors easily came in to the apartment through ventilation and when opening windows. Scents from the stairwell easily came into the apartment through the letterbox or the chink of the outer door. They described that there were lots of scents in the stairwell both from neighbors and from cleaning of the stairwell and from the laundry room (depending on where it was placed). One informant (age 52) wrote:

I am constantly exposed to triggers in my home, which is a condo in a stairwell with four apartments. The stairwell stinks of after shave, laundry detergents and fabric softener and of scented candles or suchlike. It might be fairly fragrance-free once out of 50 times. I have recently paid for the installation of a new door (without letterbox and better isolated) towards the stairwell. It has become a bit better now – before I could without warning get ill from the odors in the stairwell.

This problem with scents and tobacco smoke from neighbors led to that their current state of health depended on which neighbors they had. Some informants reported that they had tried to inform their neighbors about the problem but they were then met by lack of understanding and irritation.
One of the informants narrated that she had put carbon filter in the ventilation to reduce scents. But sometimes when too much scents from the surrounding had came in to her apartment she had to leave and stay at her mother’s place over the night. The informants also described that they had difficulties using their balcony because of scents and tobacco smoke from the neighbors close by.

One further problem with living in an apartment was that they could not use the common laundry rooms because there was too much perfume there from other’s laundry detergents/fabric softeners and it got stuck in clothes being washed there. One informant wrote that she had put up information notes and bought non perfumed laundry detergents for neighbors. Another reported having difficulties to visit the deputy landlord’s office because it was close to the laundry room.

Living in one’s own house is the best alternative, but not affordable for everyone
Living in an own house was described as being the best alternative because it was where they could stay most healthy. Therefore those who had the possibility to do so, lived in an own house. Others narrated that they should have needed an own house to stay well but they could not afford it. One informant (age 61) stated: “Preferably I would need a little house of my own with a private entrance. But my finances do not allow it.”

Some problems could arise even though living in an own house if they had neighbors too close by. Then scents and smoke from wood heating could blow over to them. Some informants described that they therefore were not always able to be in the garden and needed to put carbon filter in the ventilation. Furthermore it felt awkward to discuss the problem with the neighbors.

Being forced to move often in search of a suitable place to live
The informants described that they had been forced to move, because of their SHR, to find a more suitable place to live. Two of them narrated that they had been forced to move several times since they got SHR because it has been so difficult to find a place to live where they did not get ill of scents. One of them (age 53) reported:

It has been impossible for me to find a place to live where I can stay well. I have been declined help from authorities and have moved eight times since I got seriously ill in July 2003. I have lost everything I owned... I have lost my home and my company. I have been forced to leave my daughter, my friends and qualified health care in search of a suitable place to live.

Two of the participants narrated that they at the present moment were considering moving to find a more suitable place to live.

Many factors has to be taken under consideration when choosing a place to live
When choosing a place to live many factors needed to be considered before making the choice. The location of the house or apartment was important because of smells from the surrounding. It could not be too close to a motor road, industry/factory, an airport or a laundry room. It was also better not to have neighbors too close by, because of scents and smoke from them. Since they could not use common laundry rooms they needed to have the possibility to have an own washing machine where they lived. They also needed to have the possibility to air clothes and other things. Houses with mold problems were also important to avoid. One informant (age 47) narrated:

Problems with smoke from neighbors that burn wood off and on. ...We have off and on considered moving. I feel very unsure about that idea. My husband has, for example, suggested that we instead of living in a private house should buy a town house. On my behalf there will be a problem with neighbors who are smoking close by, so that I cannot use the patio. I am also worried about mold, to end up in a house with that kind of problems. ...To live in an apartment and being exposed to others tobacco smoke, perfume etc. That I rather do not want to put myself through. I live relatively good right now, a residential area in a smaller town, clean air with no heavy industry close by, no larger motor road close by and for the moment not too many wood heating neighbors.
Scents from previous residents cause problems
When moving in to an apartment or a house, problems arose because there were scents there left from previous residents. Therefore they needed to clean away scents and they had exchanged white goods, cupboards and other materials that had a scent left in them, if it was possible. One informant (age 25) wrote: “I still cannot use my bathroom cabinet in my present home because the previous resident kept perfumed products there. Despite the fact that I have lived here for almost a year now”

Financial security
The content area financial security resulted in four categories, with subcategories in one of the categories, which are showed in table 2. The results showed that they had a reduced income in combination with increased expenses and they had difficulties to get the support they needed from authorities. This created an insecure financial situation and they could be forced to depend on a husband/partner. Some had difficulties to manage their finances, especially if they lived alone.

Table 2. Categories and sub-categories regarding financial security.

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<td>Reduced income due to difficulties to earn one’s living</td>
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<td>Increased expenses for housing</td>
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Reduced income due to difficulties to earn one’s living
Because they got ill when being at their workplace due to scents there and it being difficult to find a new workplace free of scents, many of the informants could not work anymore. Some of them tried working part time. Working only part time, being sick listed or having sickness pension led to reduced income. Difficulties to get sick listed or getting life annuity for some of them, led to even more reduced income and being forced to apply for social allowance. One informant (age 61) who had gotten sick after working in a "sick building" wrote: "I got sick in 1992. Since 1993 I have been excluded from the labour market due to my occupational injury. My finances were drastically changed for the worse. I did not succeed in finding a new workplace where all of the staff is free of scents and the workplace is optimal for my condition"

A student narrated that she had not applied for summer job since she got sick because she was afraid that it would not be possible to make it work with her odour sensitivity. Another informant described that she had quit her job and started an own business but she could not work full time and worried about her finances since her sickness benefit was low because she ran her own business. She described that it was difficult to plan her assignments due to her unstable health, this made her feel unreliable and she felt ashamed to bring up her health condition with new business associates.

Increased expenses due to living with SHR
Increased expenses for housing
The informants narrated that they had got increased expenses for housing since they got ill. Some of them had been forced to move several times in search of a suitable place to live, which became expensive. Needing an own house to be able to stay well was also an increased expense and several
of them could not afford it. The informants also described that they needed to do some expensive housing accommodation. This could be to get rid of scents from previous owner or to buy and install an own washing machine since they could not use the common laundry room. One informant (age 45) stated: “The place where i live is completely decontaminated of scents, everything from white gods to material with a scent. ...The housing accommodation has been the most expensive” Another informant had needed to change her front door to a new door without letterbox and better sealed to avoid getting scents from the stairwell into the apartment and it had become expensive.

**Increased expenses for necessary running expenses**

The informants described that they needed to wash their clothes and take showers more often now because when they came home, they needed to get rid of scents that had stuck on them from the surrounding environment (like sitting in a chair where a scented person have sat before or being in a room full of scented people or where they use air freshener). They also needed to wash new clothes that they had bought because they often smelled perfume from being sprayed or just by being in a store with a lot of scents. The new clothes often needed to be washed several times to get rid of the scents. This extra washing and showering became an increased expense for them. New things and clothes they had bought which they could not wash out the scent from, they were forced to throw away, this led to more extra expenses. One informant (age 52) wrote:

> I can also add some more here about the problem with newly bought clothes, bags, furniture etc. Everything that is possible to wash needs to be washed, sometimes several times because these things are impregnated with perfume which is made to last and to emit scent when on, for example, has them against the body, warmth and moisture.

Furthermore they narrated that they thought that non perfumed products often were more expensive then the perfumed alternatives and that it was a limited supply of the non perfumed products and they never were on sale. Some of them sometimes also bought non perfumed products to give away to other people to facilitate the situation. Other things that were brought up as increased expenses were filters to air purifier, face masks and one informant also mentioned that she thought that the holiday trips had gotten more expensive because she could not share a room with others.

**Increased expenses because of being in need of an own car**

The need to have an own car because of difficulties to use public transportation led to increased expenses and some of them narrated that they could not afford to have an own car even though they really needed it. One informant also narrated that she could not afford the drivers licence and therefore she had no possibility to have an own car.

**Increased expenses as a result of trying alternative medicine**

One informant narrated that she had tried alternative medicine, because of the lack of treatment/medicine for SHR, but it was expensive. Two others expressed a wish to try alternative medicine but they could not afford it since it was not possible to get through the ordinary health care system.

**Lack of support from authorities**

Having difficulties to get understanding from the social insurance office and get sick listing approved were common. Some narrated that seeing an understanding physician and/or getting a diagnosis facilitated getting sick listed. One informant narrated that it had been especially difficult because the diagnose SHR did not exist when she got ill. Another informant narrated that she thought that it was more difficult to get understanding with new stricter rules for sick listing. She had also experienced that the social insurance office did not trust her physician’s assessment of her working capacity. She also narrated that she had gotten support from her physician and a welfare officer in her struggle against authorities. Some of the informants had got SHR after long term or heavy exposure to chemicals at the workplace. Some of them wrote that they had applied for getting it approved as an occupational injury but it was difficult to get it approved. Some had got it approved after a long struggle and some were still struggling. The same struggle begun again when applying for life annuity and some succeeded eventually but some had not yet succeeded. One of
them wrote that her financial situation was tolerable now because she had finally after long struggle got life annuity approved. Another of them narrated that she had applied for social allowance while having a tough time during the struggle for life annuity but the social allowance was also difficult to get. Another informant (age 53) shared her experience of not getting understanding and support from authorities:

_It took almost three years to get my sickness pension approved by the social insurance office through the county administrative court. ... I have over and over again applied for financial aid (for expenses due to the disease) among other authorities, through the social insurance office (disability allowance) but everything I apply for is turned down._

Two of the informants narrated that they had got allowance for having an air purifier/air condition in their home.

**Difficulties to manage the finances**

Several of the informants expressed that they had difficulties to manage their finances or that they were worried over their finical situation. The worries were about future finances overall and in specific about not being able to earn one’s living by working, not getting enough sickness benefit, losing the sickness benefit. One of the participants narrated that her finances had been completely ruined because of the disease. She felt that she lived in misery and she could not even afford some of the essential expenses. Another informant had been forced to lend money from her parents to manage her finances. Yet another had been forced to lend money from her pension money.

One of the informants (age 64) who lived with her husband stated: “Financially, it should have been very difficult for me to manage without my relatively healthy husband!”

**Social relationships**

The findings from the content area social relationships resulted in four categories with subcategories in two of them, which are showed in Table 3. The results showed that their social relationships had been affected by SHR. Socializing with others had become hard and troublesome, they had become limited in doing social activities. They got support from some but these persons became limited. The fourth category, refusing to change one’s social interaction, was represented by only one of the informants. Some informants expressed in overarching terms that they thought that their social relationships had been affected in a bad way and become difficult.

**Socializing with others has become hard and troublesome**

*Getting ill when socializing with other people due to their scents*

The informants described that they got ill when they socialized with other people wearing perfume or scented products or people smelling tobacco smoke or mould. They could get ill for several days after exposure. One informant (age 23) stated: “Furthermore, one tough part of the disease is all the delayed symptoms, then I can be laying on the couch for several hours and barely being able to get up.” Meeting people indoors could be worse. Meetings with friends sometimes had to be terminated when getting ill. Another informant (age 44) narrated: “I hesitate to hug others at social gatherings because it could sometimes be like putting the nose in the perfume bottle.”

*Feeling bothersome when asking others to refrain from scents*

They narrated that they asked others to refrain from wearing scents when they should meet, but they felt bothersome when doing so and it felt hard to be forced to constantly inform and remind others to refrain from wearing scents and to be depending on that others made changes for their sake. Asking others to refrain from scents was experienced as invading others integrity and being forced to cross the line of social acceptable behavior. Further, they described that it felt difficult to explain and set limits for others about scents. One informant (age 44) wrote: "Everyone who cares wants to do what they can but it feels like I am restraining their freedom. To go as far as to ask my friends to wash and rinse their clothes in laundry products without perfume feels far away..."
Table 3. Categories and sub-categories regarding social relationships.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sub categories</th>
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<tbody>
<tr>
<td>Socializing with others has become hard and troublesome</td>
<td>Getting ill when socializing with other people due to their scents</td>
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<tr>
<td></td>
<td>Feeling bothersome when asking others to refrain from scents</td>
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<td></td>
<td>Feeling different</td>
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<td></td>
<td>Lack of understanding and respect from friends and relatives</td>
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<tr>
<td>Have become limited in doing social activities</td>
<td>Social activities must always be carefully planned and prioritized among</td>
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<td></td>
<td>Trying to do social activities where problems with scents are minimized</td>
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<td></td>
<td>Cannot receive scented visitors at one’s home</td>
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<td></td>
<td>Getting isolated</td>
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<tr>
<td>Getting support from some but it makes them limited</td>
<td></td>
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<tr>
<td>Refusing to change one’s social interaction</td>
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**Feeling different**

One of the informants described that since she needed to tell new acquaintances quite soon that she get ill of perfume she felt like she got identified as the odor sensitivity person instead of her personality. She also felt that people stared at her when using the face mask. She thought that it seemed like her partner and friends accepted the mask though. She also described feeling outside when friends talked about things that were completely natural to them but difficult or impossible for her because of her condition. Further she narrated that she felt like she was forced to behave in way that was not herself because of the SHR. Another informant also described that the SHR had made her be in a way that was not herself and that this change of her as a person also affected her friends.

**Lack of understanding and respect from friends and relatives**

The informants experienced lack of understanding from friends and relatives. This was both about general understanding of their situation and in specific they described friends and relatives having difficulties to understand that perfume is also perfumed products like soap and laundry products, that perfume can remain for a long time in for example clothes and that only a little perfume could cause symptoms. One of the informants narrated that she thought that it could be more difficult for others to understand because the condition is invisible and the symptoms can arise with a delay from the time of exposure. She also described that when she was very ill in the delayed symptoms she could be too ill to leave the home and she closed herself in so no one saw her. Another informant (age 41) wrote: "... they do not believe me, “my disease is not visible”. Sometimes I have been mocked and ridiculed. I do not get ill on order so that I can show how things are for me. It is always a trial to “socialize with others”, some understand and others do not."

When asking others to be free of scents conflicts could arouse with people who did not understand or did not want to refrain from scents. Further, their friends and relatives sometimes forgot to not wear scents when they should meet or forgot that there are places like nightclubs that they cannot go to. The lack of understanding and respect led to that they could no longer socialize with all of their friends and relatives. Some persons just disappeared when facing the facts and in other cases they were forced to make the choice to stop seeing persons who were scented. Loosing friends and relatives made them sad. One informant (age 47) wrote: “...it is worse (regarding understanding) with friends, relatives and acquaintances. The only way out in these cases is to give up seeing those who do not understand since I get so ill and stay ill for several days.”

Two of the informants reported that they had friends who disappeared at first but had come back later. They thought that it can take a long time both to understand and to find solutions together.
Have become limited in doing social activities

Social activities must always be carefully planned and prioritized among

Social activities needed to be planned beforehand. They needed to carefully plan when and where to meet and inform all attendants to refrain from scents. Therefore they experienced that it was difficult to be spontaneous. One of the informants (age 25) wrote: "It is difficult to do social activities spontaneously. Many preparations are needed if I am, for example, going to a party. To contact everyone beforehand and make sure that no one is scented. This is very though because I am actually a very spontaneous person."

When socializing with others they could get exposed to scents even if they tried to avoid it by asking others to refrain from scents (because others forgot or did not understand or because they felt too bothersome when asking others to refrain from all scents, so choosing not to do so). Therefore they also had to take into account days of being sick after social activities. They also needed to prioritize which social activities they most wanted to attend, which felt worth getting ill for, because they could not attend all activities without being too ill all the time. One informant (age 44) stated:

*All this (finding it difficult and bothersome asking other to be free of scents) leads to me often choosing not to do social activities that do not feel worth getting ill for. Making these adjustments and priorities is something I struggle with every day and every week since I would very much like to participate in all of the children's activities, parent meeting etc. It is tough.*

Trying to do social activities where problems with scents are minimized

Some of participants narrated that they tried to meet friends outdoors because it was easier. One of them described being active in an outdoor life association but she reported that there were still problems. Smoke from the camp fire or others applying perfumed sun lotion could cause symptoms. Therefore she could get ill and then having difficulties to keep up with the rest at the activities. She narrated that it felt tough detaining the group when she was ill. Another informant described that she spoke on the telephone and e-mailed friends as an alternative since she could not see them so often because she got too ill when meeting them.

Cannot receive scented visitors at one's home

The informants described that they could not receive scented visitors at their home. The home needed to be free of scents. When they have had scented visitors, furniture’s could smell from the visitors scents. One informant (age 41) wrote: “My home is free of scents as far as possible, an oasis where I can relax, so I cannot receive just anyone in my home.” Some of the informants narrated that if visitors arrived scented, they could be forced to reject them but it felt very tough and conflicts could arise. One informant (age 45) stated: “Everyone knows that I cannot receive anyone in my home who smells (if someone forgets) I must refuse them, and that is so tough. I do not think that I will ever get used to this.” Some of the informants kept non-perfumed clothes to lend to visitors. One informant narrated that friends and relatives avoided visiting because it was too troublesome to avoid scents.

Getting isolated

Some of the participants described that they felt isolated. They narrated that they lived isolated in their homes and their social life had shrunk to a minimum. One informant (age 53) reported: “Nowadays I live completely isolated in principle seven days a week, and I hope that I will not go crazy. It is almost impossible for me to socialize with other people.”

Getting support from some but it makes them limited

The people they lived together with, like their husband, partner, children (living at home) or other cohabitants needed to be free of scents. They described getting full understanding and support from them but they felt that they put limitations on them. One informant (age 52) stated: “This affects to a very large extent also my partner and his possibilities to a normal social life.” Another informant (age 23) narrated:
If my partner goes to a bar one night I am the one with a hang over the following day because of him smelling perfume when he comes home. ...I get very dependent on my partner, which is tough on both him and me. If he meets friends or goes out somewhere he often comes home and smells. Clothes and hair smells and it is not always possible to wash out. I get sad when he comes home (because of getting ill of the scents on him) and then he cannot hug me because then I get worse. It often feels like I am watching over him so he should not forget things that could make me ill.

The informants described that some friends and relatives stood by them which felt good. They described how remaining friends try to show consideration and use products without perfume when they meet and that some had even switched to products without perfume for their sake.

Some of the informants narrated that it could be difficult for friends and relatives to be free of scents even if they wanted to be so, because perfume from laundry detergents and fabric softener remain for a long time in the clothes or if they washed their clothes in laundry rooms shared with others, their clothes got perfumed from others laundry products. One informant (age 23) wrote:

Even if people want to be free of perfume it is not always possible. I have a friend who switched to laundry and hygiene products without perfume when I got ill, but I can still not see her indoors because she washes in the same laundry room as others who have “monstrous” laundry detergents.

Refusing to change one’s social interaction
One of the informants reported that she had not changed anything in her social interaction. She narrated however that she did not let her friends smoke when they met (but she still got ill by the remaining smell of smoke in their clothes). She had most problems with smoke and mold and she stated that people who instead had most problems with perfume maybe needed to act differently. She (age 47) wrote:

I think it is more important to meet my friends and relatives and therefore I expose my self to these situations even if I know that I will be very ill for days afterwards. It is naturally open to discussion whether this is wise or not, but as mentioned before, I do not want my disease/symptoms to control my life. My friends have therefore not needed to change anything in their way of life in order to meet me. I am simply not the person who makes demands on others in that way. I probably find it difficult to take that position and I do not either want to expose others to being controlled by my disease.

Themes
Six themes permeated the categories in all three content areas: “Being limited”, “Being forced to behave incompatible with your true personality”, “Experiencing a lack of understanding and respect from others”, “Experiencing insecurity”, “Being dependent on others” and “Being forced to choose between the plague and cholera”.

Being limited
The lack of accessibility made them very limited to participate in society. They were limited to work, to study, to transport themselves and to go on holiday trips, to do leisure activities, to visit public building and facilities. Their social life was also limited because they got ill when socializing with people due to their scents. The combination of a reduced income because of the difficulties to be able to work and the increased expenses due to their condition made their finances limited especially since they had difficulties to get some financial support from authorities. These limited finances placed further limitations on their life and could also increase other limitations, for example not being able to purchase a car (that they needed because their difficulties to use public transportation) and then get limited in transportation. These limitations in their life could also lead to them becoming isolated.

Being forced to behave incompatible with your true personality
Underlying several categories it became clear that they in their attempts to avoid scents were forced to behave in a way which they felt was not who they really were and did not want to be. When asking others to refrain from wearing scents they were forced to act in a way which is not socially acceptable behavior and invades others’ integrity. If someone came to visit them wearing scents
they could be forced to reject them and risk being perceived as unkind and disagreeable. They could be forced to leave in the middle of a meal at a restaurant or in the middle of a movie or a gathering with friends, which could be perceived as acting very strange. Their social life became difficult and with limitations which led to that they could no longer be as social as they wanted to be. If they were a spontaneous person they could no longer be spontaneous, because now everything needed to be carefully planned both because of trying to minimize exposure to scents and also because of the need to plan sick days after being exposed to scents. Further they could no longer do many of the things that they used to enjoy doing before without getting ill, like travel or go to the gym, nightclubs, concerts etc. Being forced to quit working and being sick listed could also be to change who they were. Regarding work, one of the informants described that her unstable health made her seem unreliable to her business associates and she felt ashamed to bring up her health condition with them. This, feeling ashamed, was something that seemed to be underlying some of the informant’s experiences. This was about being ashamed of having to behave and act in a strange way and also about having to use a carbon filter mask in some situations and run the risk of people staring at them.

**Experiencing a lack of understanding and respect from others**

That they experienced a lack of understanding and respect from others became obvious in several categories in all three content areas. They experienced this from friends, relatives, neighbors, colleagues/fellow students, health care personal, employer and authorities.

**Experiencing insecurity**

Reduced income in combination with increased expenses and that they had difficulties to get the support they needed from authorities created an insecure financial situation. It was difficult or impossible for them to find a suitable place to live which caused an insecure situation regarding housing. Further they also experienced insecurity regarding social relationships, not knowing if others would understand and respect the need to refrain from scents.

**Being dependent on others**

They became dependent on that other people in their close surrounding, like husband/partner, family, relatives, friends and colleagues/fellow students, changed their choice regarding scents if they should be able to socialize with them or be able to work/study. Getting ill or staying well in their own home became dependent on their neighbors (for example if the neighbors were smokers or not or if they used a lot of perfume or not) if they had neighbors too close by, worst so when living in an apartment. Being dependent on others was also about needing help sometimes, with for instance shopping. Regarding finances they could get dependent on their husband/partner. Living with SHR could lead to increased expenses which could be impossible for them to handle by themselves if they had gotten a reduced income and for some difficulties to even get some income at all. One larger expense which they could make them very dependent on their husband/partner for was owning a house to live in.

**Being forced to choose between the plague and cholera**

One of the informants stated: “I had to choose between the plague and cholera”, regarding where she could be in the workplace so that she would not be where there was too much scents. This was a specific situation she described, but this, to be forced to choose between the plague and cholera was something that appeared underlying their experiences overall. Either conscious or unconsciously they had to make this choice constantly in several situations in life. They had to choose between socializing with friends and relatives who were scented and get ill or to not socialize with them but instead have a reduced social life and spend much time alone. Another choice was between getting ill when socializing with their friends and relatives or asking them to refrain from wearing scents. When asking others to refrain from wearing scents they felt bothersome, being forced to invade others integrity, and further they could risk being met by a lack of understanding and conflicts could arise. In their relation with their husband/partner and family living at home, they were also torn
between two evils. They felt grateful that they got complete support from them but they also had bad conscience because they felt like they limited them. Leisure activities is another example where they had to choose between doing things they loved like going to the cinema, theater or restaurant and then get ill or to not do this and stay well but then missing out on these activities. Regarding work, they had to choose between giving it up (with the loss of income, social life at work, career possibilities and work identity), or to try working even though getting ill all the time (but it could be impossible because of not being able to manage the work when being constantly ill). Another alternative was to try to get accommodation at the workplace but then they could risk not getting understanding, respect or support from employer and colleagues. In the choice of a suitable place to live, this choosing between the plague and cholera could also occur. At one place it could be free of smoke from wood heating but instead they could have problems with perfume and tobacco smoke from neighbors, and at another place it could be the reverse.

**DISCUSSION**

**Discussion of results**

The purpose of the present study was to illuminate how individuals living with SHR, experience its impact on accessibility, financial security and social relationships.

The results regarding accessibility showed that the informants experienced an extensive lack of accessibility in society. It was difficult to move around in society, to visit public buildings and facilities and it was almost impossible to find a suitable place to live.

No other study has focused on exploring accessibility for people living with SHR or MCS, but the studies by Larsson and Mårtensson (2009) and by Skovbjerg et al. (2009) describe difficulties to use public transportation, going on trips, visiting work places, health care facilities and shops. Reed Gibson et al. (1996) describe difficulties in access to public spaces for people with MCS living in the USA. These findings resemble those from the present study. Difficulties to find a suitable place to live was also one major problem with accessibility showed in the present study. Problems with housing for people with MCS living in the USA have been described by Lipson (2001) and Reed Gibson et al. (1996), and they also reported difficulties to find a suitable place to live and being forced to move several times. The problems reported in these studies by people with MCS, focused on building materials, gas heating and pesticide while problems reported in the present study, by people with SHR, focused on scents from previous residents, tobacco smoke, wood heating smoke and scents from neighbors. Pesticide and gas heating is common in USA but not in Sweden, which can explain some of the differences in focus of the problems though. These differences could also be related to differences between the conditions. Problems at the workplace for people with MCS have been thoroughly described by Reed Gibson and Lindeberg (2007) and Lipson and Doiron (2006) and these findings accord with the findings from the present study.

Accessibility is a fundamental necessary condition for participation in society (The Swedish National Institute of Public Health, 2005). As described in the present study, there is an extensive lack of accessibility for people with SHR which makes it difficult for those people to participate in society. According to The Swedish National Institute of Public Health (2005) a lacking accessibility makes it impossible for the individual to be in control of his/her own existence and it contributes to the creating and maintaining of "being left outside" (the Swedish term: utanförskap) and this affects the health in a negative way.

Domain number one in the public health policy "Participation and influence in society" is clearly affected in people with SHR, but the lack of accessibility also has secondarily effects on the domains "Economic and social security", "Healthier working life" and "Increased physical activity" because of difficulties to visit workplaces, gyms etc.

The findings from the present study regarding financial security showed that they had a reduced income in combination with increased expenses and difficulties to get the support they needed from authorities. This created an insecure financial situation and they could be forced to depend on a husband/partner. For some it could be difficult to manage their finances, especially if
they lived alone. Financial security was not explored in the studies by Larsson and Mårtensson (2009) and by Skovbjerg et al. (2009), but studies from the USA of people with MCS by Lipson and Doiron (2006) and Reed Gibson et al. (1996) have touched this subject briefly. Findings from these studies show that people with MCS have difficulties to get workers compensation and disability benefits because they have difficulties to get a medical diagnosis.

Regarding getting a diagnosis and getting disability benefits there are important differences between having SHR living in Sweden and having MCS living in the USA. The social insurance system differs between the countries, and in contrast to MCS, SHR have the latest years become a diagnosable condition in Sweden by using the capsaicin provocation test. It does not have an own ICD10 number though so it is not a "real" diagnosis in that way but it is diagnosed under R068; other and unspecified abnormalities of breathing. The participants in the present study all had gotten the diagnosis SHR but they still had problems getting support from authorities with getting sickness benefit, life annuity and financial support for increased expenses.

It has been almost impossible for patients with SHR to get financial support from authorities for increased expenses like buying a car or getting housing accommodation (E. Millqvist, personal communication, June 11, 2009). According to The Swedish National Institute of Public Health (2005), both the physical and the mental health is affected in a negative way by financial insecurity.

The results from the present study showed that their social relationships had been affected by SHR. Socializing with others had become hard and troublesome, they had become limited in doing social activities and they got support from some but these persons became limited. The fourth category, refusing to change one’s social interaction, was represented by only one of the informants. The studies by Larson and Mårtensson (2009) and Skovbjerg et al. (2009) show resembling findings as the present study regarding social relationships, showing limitations in social activities, lack of understanding from others and getting support foremost from their immediate family.

Studies show that social relationships have a great importance to an individuals wellbeing and also for mortality in cardiovascular disease and the over all physiological and psychological health and especially important are the relationships at the individual level. (The Swedish government proposal, 2007/08:110).

The category refusing to change one’s social interaction illuminates one informant’s choice and she acts in the same way regarding work, not having changed anything in her work situation. Her behaviour may be compared to the theme "disparagement of one’s own personal experience" that Larsson and Mårtensson (2009) describe representing two of the informants in their study. Her behaviour may be explained her trying to avoid being stigmatized (read more about stigma later on in the discussion) and by the theme, being forced to choose the between the plague and cholera, found in the present study. It may also be explained by her getting ill foremost by the smell of smoke and mould and not as much by perfume. Perfume is of more frequent occurrence in society than mould and smoke (since the extended rules of smoke prohibition). She might also represent people who have a less severe SHR (having a lower score on the CSS-SHR).

Six themes permeated the categories in all three content areas: “Being limited”, “Being forced to behave incompatible with your true personality”, “Experiencing a lack of understanding and respect from others”, “Experiencing insecurity”, “Being dependent on others” and “Being forced to choose between the plague and cholera”.

Being limited illuminates that these people with SHR have a disability, if The Swedish National Board of Health and Welfare’s definition of disability is used. Larsson and Mårtensson (2009) also describe experiences of limitations in life situations. Skovbjerg et al. (2009) illuminate experiences of limitations and suggest that MCS can be a disabling condition. Reed Gibson (1993) and Lipson (2004) describe MCS as a hidden disability.

Being forced to behave incompatible with your true personality is an aspect of living with SHR that can be stigmatizing. According to Goffman (1972) the term stigma refers to an attribute that is deeply discrediting and stigma has a double perspective meaning tahat a person can be either discredited, having a visible sign of being different or he/she can be discreditable, not being immediately perceivable as different. Stigma can be related to physical defects, individual character
that is perceived as weak (like mental disorders or dishonesty) and race or religion (Goffman, 1972).

In the present study the informants described being forced to act in a way which is not socially acceptable behaviour, for example, when asking others to refrain from wearing scents and they could be forced to act strange when being forced to immediately leave a place with a lot of scents. These behaviours are stigmatizing and so is also the aspect some described about feeling ashamed over not being reliable at work (due to the disease) and feeling ashamed of wearing a face mask in public. Lipson (2004) describe MCS as a stigmatized condition, both because of them being forced to behave strange and because of the psychologization of the condition which makes them being perceived as liars or hypochondriacs.

This leads to the theme, experiencing a lack of understanding and respect from others, which is also attached to stigma but it is also related to gender aspects. The informants in the present study felt that they were not believed and understood by other people which led to problems both in social relationships and in interaction with authorities. In a study by Åsbring and Närvanen (2002) about women’s experiences of stigma in relation to chronic fatigue syndrome (CFS) and fibromyalgia, they found that above all two aspects are stigmatizing: Being psychologized by others, in particular by physicians, and that their moral characters were called into question in interaction with others, being accused of lying.

Medically unexplained disorders, for example fibromyalgia, CFS, irritable bowel syndrome and MCS are most common among women and these patients often receive psychiatric diagnoses like somatization disorder, depression or hypochondria (Malterud 2000). According to Banks and Kaschak (2003) there is a tendency to ignore or minimize women’s symptoms and overdiagnosing psychiatric disorders. They point out that multiple sclerosis was formerly considered a mental disorder caused by “female hysteria” and it was not until 1996 that it was recognized as an autoimmune reaction linked to viruses. Today, women with MCS, CFS and fibromyalga are often referred to as ”hysterical” (Banks & Kaschak, 2003). This tendency to dismiss women’s symptoms/medically unexplained disorders as being imaginary, or as caused by psychiatric disorders before its’ cause is determined contributes to the stigmatization of women with conditions like SHR or MCS, and them not being understood and taken seriously by others.

The next theme, experiencing insecurity and the following theme, being dependent on others, illuminates that this condition can become a trap for women, making them dependent on their husband/partner, especially financially. They could end up with a very low or even without income together with increased expenses like the need of an own house and an own car and other increased running expenses due to the disease, but not getting support from authorities. Their only way out then could be to become totally dependent on having a husband/partner to provide for them.

The theme, being forced to choose between the plague and cholera, has not been illuminated in other studies of people living with SHR or MCS. This is an aspect of living with SHR that is important to spread knowledge about to gain better understanding of their situation and their behaviour. As mentioned before this aspect was concretely apparent in several situations in their lives, but "being forced to choose between the plague and cholera" is also an overarching conclusion about the effect on the health determinants. If they choose to avoid scents, the health determinants accessibility, financial security and social relationships are all affected in a negative way. On the other hand, if they choose to expose themselves the health determinants is affected in a positive way, but they get ill in SHR-symptoms and therefore may not even be able to gain the positive affects because of not being physically able to engage in social activities, work etc.

Further studies about how it is to live with SHR are needed and given the results about the effect on the persons closest to them, it may also be of importance to study their experiences. Furthermore, focus group and survey studies may be carried out to investigate more about accessibility for people with SHR and possible improvements of accessibility.

Methodological considerations
When reporting results from studies using qualitative content analysis Graneheim and Lundman (2004) suggests that the measures for achieving trustworthiness should be credibility, dependability
and transferability.

Regarding credibility, one weakness of this study is that a purposeful sample has not been made to get participants with various experiences. The sample gathered from advertisement in this study still ended up in a wide range of age and geographic distribution even though it was limited by being only women and an overrepresentation of sick listed participants. The recruitment through the website for people with odor intolerance was however strategic for getting people who were adept at writing and willing to write about their experiences of living with SHR. The recruitment was in this way carefully matched with the data collection method. The credibility regarding the analysis process has been enhanced by having the co-supervisor check after every step in the process so it is not done by only one researcher. Judging of the credibility has been facilitated by documenting the process of choosing meaning units and condensing and abstracting them into becoming codes. When creating the categories the strive has been to achieve what Graneheim and Lundman (2004) describes as the categories being internally homogeneous and externally heterogeneous. This has however been quite difficult to achieve completely in the present study because of the experiences of the participants being so intertwined with each other and affecting each other. Graneheim and Lundman (2004) point out that because human experiences have an intertwined nature it is not always possible to achieve this goal when analyzing texts about experiences. To enhance credibility, quotations from the participants written descriptive texts have been used in the presentation of the findings. The quotations have been carefully selected to represent the results and they have been translated into English using a dictionary and the translation have been checked by the supervisor who is bilingual in Swedish/English.

The data collection in the present study has not extended over a long time, which is good for the dependability. To facilitate transferability a background questionnaire and the CSS-SHR was used and the selection and characteristics of the participants as well as the data collection and the process of analysis is clearly described.

The author´s pre-understanding could have affected the results, but efforts have been made to minimize this effect as much as possible. The researcher´s effect on the respondents when collecting data was minimized by choosing descriptive texts written by the participants instead of interviews, but the instructions and questions given to the respondents could have affected their answers. The analysis of data could also have been affected, but the author´s pre-understanding has a positive effect too, by facilitating understanding of the participants´ experiences.

One strength with the present study compared to the resembling studies by Larsson and Mårtensson (2009) and by Skovbjerg et al. (2009) is that the present study presents more detailed descriptions which creates a more complete picture of their situation and therefore gives a deeper understanding of their experiences. But making a thorough description may also have led to the result becoming too extensive so it may have been wiser to have focused on only one factor thoroughly instead. On the other hand these three factors are closely related and described together they create a whole intertwined picture which increases the understanding of these individual´s situation. One weakness compared to the studies by Larsson and Mårtensson (2009) and by Skovbjerg et al. (2009) is that in the present study the sample was recruited by advertising and in the other two studies there was a strategic sample. Advertising could have led to getting more severely affected individulas with SHR because they could have been higher motivated to participate in the study then individuals with less severe SHR. The mean score on the CSS-SHR in this group was 52.25 which is quite close to the top score 55 and may therefore indicate that the individuals in the present study has severe SHR.

**Implications for public health work**

According to the national action plan for handicap policy, society should be formed so that everybody with impairments can participate completely in society (The Swedish government proposal, 1999/200:79). Making society completely accessible for people with SHR can be difficult though because it would invade on other people´s integrity. Two of the basic ethical principles, beneficence and autonomy come into conflict with each other in this matter. SHR should however
be considered in work with improving accessibility for people with impairments and there are some improvements that should be able to be considered regarding accessibility for people with SHR, for example: Perfume departments/shops in malls and airports does not need to be placed so that they are necessary to pass through. Strongly scented products do not need to be placed at entrances and exits in shop, and non perfumed products could be placed separate from the perfumed products. There could be public lavatories free of perfume like there are accessible lavatories for people with motor-impairments. At hotels there should be possible to have a few rooms where perfume is prohibited like smoke free rooms. It should also be possible to make accessible housing for these individuals in form of special buildings to share with others with SHR or financial aid to afford a suitable place to live and necessary housing accommodations.

According to the national action plan for handicap policy, there should be a supply of accessible housing for people with impairments which makes it possible for them to choose, in a reasonable extent, which town and which kind of place to live in (The Swedish government proposal, 1999/200:79). The Asthma and Allergy Association made an inquiry year 2007, about housing for people with allergies and only three towns in Sweden had some kind of living where scents were restricted to some extent.

It is important for the financial security that people with impairments can get compensation for increased expenses related to their condition (The Swedish National Institute of Public Health, 2008). Financial support should be able to get for reasonable increased expenses due to living with SHR. To improve the social aspect the most important action is first to spread knowledge about SHR and how it is to live with the disease in order to increase understanding from others.

Conclusions
Living with SHR can affect social relationships to being limited and troublesome, create a financial insecure situation and make it difficult to participate in society because of a lacking accessibility. Regarding these health determinants, living with SHR can result in "being forced to choose between the plague and cholera". If they choose to avoid scents, the health determinants are affected in a negative way. On the other hand, if they choose to expose themselves the health determinants is affected in a positive way, but they get ill in SHR-symptoms and therefore may not even be able to gain the positive affects because of not being physically able to engage in social activities, work etc.

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