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Experiences of problems in individuals with hypersensitivity to odours and chemicals

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Aim. The purpose of the study was to describe how individuals with hypersensitivity to odours and chemicals handle their problems.

Background. One group of patients we often encounter consists of those with upper and lower respiratory problems who also have a pronounced sensitivity to odours and chemicals. Earlier studies have shown that these symptoms can be related to sensory hyperreactivity (SHR). This hyperreactivity is characterised by respiratory tract symptoms triggered by odours and chemicals, along with high sensitivity to inhaled capsaicin and a positive score on the chemical sensitivity scale for SHR. However, there is still a lack of studies in which SHR sufferers describe their situations in their own words.

Design. The study was conducted using a qualitative approach.

Methods. Eight individuals with confirmed SHR were selected from a population-based epidemiological study and interviewed. A qualitative content analysis was performed on the data.

Results. Four themes emerged from the data analysis: Limitations in one's life situation, Lack of understanding from others, Concern that the symptoms will develop into a serious disease and Disparagement of one's own personal experience. The results show how individuals manage their daily lives with the help of various strategies, how they relate to other people, how they cope with their concerns and the fact that they sometimes choose to disparage their own experience of their problems.

Conclusion. The results indicate that people with SHR experience limitations in their life situations. These limitations consist of the adjustments they make to avoid triggering factors.

Relevance to clinical practice. To improve care, nurses need to know how people experience SHR and how they cope with their hypersensitivity to odours and chemicals.

Key words: care, nurses, nursing, qualitative interview, sensory hyperreactivity

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Introduction

One group of patients we often encounter consists of those with upper and lower respiratory tract problems who also have a pronounced sensitivity to odours and chemicals. Hypersensitivity to odours and chemicals in the surrounding environment is a common occurrence in industrialised countries; the self-reported prevalence among a general population is between 16–33% (Meggs *et al.* 1996, Kreutzer *et al.* 1999, Johansson *et al.* 2005). Such hypersensitivity can be defined as the experience of feeling ill upon exposure to weak concentrations of commonly occurring chemicals in the environment (Nordin *et al.* 2003, Andersson *et al.* 2008). In the published reports, Multiple Chemical Sensitivity (MCS) is often used as a collective term for chemically triggered symptoms involving multiple organ systems (Cullen 1987). Because there is no objective method to detect MCS, medical organisations in the USA have asserted that MCS

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cannot be viewed as an established organic disease (Gots 1995).

There are several examples of studies describing self-reported symptoms in individuals with MCS. These studies involved 140–305 individuals and used questionnaires to gather data (Reed Gibson *et al.* 1998, Reed Gibson 1999, Baldwin *et al.* 2004). An ethnographic interview study conducted by Lipson (2001) describes individuals' experiences of living with MCS and how these individuals managed and coped with their symptoms. The individuals involved in the study used essentially three types of self-treatment to cope with their symptoms. They avoided or prevented exposure to the substances they could not tolerate and they tried in various ways to detoxify themselves, as they perceived the symptoms of MCS to derive from toxic substances in their surroundings. They also used emotional self-treatment to attain meaning and to improve their quality of life, as the outside world, as encountered in the form of healthcare workers, the media and the general public, often had a negative image of them. Their symptoms were sometimes perceived to be imaginary (Lipson 2001).

Living with a chronic disease imposes strain in one's daily life. It affects relationships within one's family and also imposes a stigma in one's social life. (Rydström *et al.* 2004, Lorrie Yoos *et al.* 2005). A long-term or chronic disease is a problem that one must live with and many people employ various strategies to cope in their daily lives. Learning to use conscious coping strategies can be effective in reducing symptoms and ameliorating feelings of anxiety and stress (Ringsberg *et al.* 2002, Barton *et al.* 2003). However, one strategy is to actually avoid using coping strategies that can result in avoidance or denial of the symptoms (Barton *et al.* 2003).

Studies in Sweden have led to the theory that some individuals who are sensitive to odours and chemicals are afflicted by sensory hyperreactivity (SHR), that is, sensory hypersensitivity of the airway sensory nervous system. It is possible that hyperreactivity of the sensory nervous system in the respiratory tract and ocular mucous membranes leads to neurogenically triggered symptoms upon stimulation. One important misconception arises when hypersensitivities to odours and chemicals are conflated with symptoms deriving from the sense of smell; in fact, symptoms can be caused by odours and chemical substances even when the sense of smell is blocked (Millqvist *et al.* 1999). SHR does not extend to bronchial obstruction or bronchial hyperreactivity as measured using methacholine provocation (Millqvist *et al.* 1998, Millqvist 2000, Ternesten-Hasséus *et al.* 2002).

Capsaicin, which is the spicy substance in Spanish peppers, has long been used to study sensory nerves. It works by stimulating sensory C-fibres in the respiratory tract. Coughing can be induced by inhaling increasing concentrations of capsaicin (Hansson 1995). Individuals who are sensitive to odours and chemicals have been shown in several studies to cough significantly more upon inhaling capsaicin than do healthy control subjects or individuals with well-medicated asthma. Capsaicin inhalation test is an objective test and has been used in controlled studies (Millqvist *et al.* 1998, Millqvist 2000, Johansson *et al.* 2002, Andersson *et al.* 2008).

For most individuals, hypersensitivity to odours and chemicals entails various degrees of impact on and disruption in their daily lives (Johansson *et al.* 2005). A questionnaire, the Chemical Sensitivity Scale for Sensory Hyperreactivity (CSS-SHR), has been prepared and evaluated for its ability to measure and quantify emotional reactions and disruptions in daily life because of odorous/pungent substances among individuals with SHR (Nordin *et al.* 2004a,b). However, SHR is not yet an established diagnosis. The proposed definition of SHR is a condition involving respiratory tract symptoms triggered by odours and chemicals, where the sensitivity to inhaled capsaicin is greater than in healthy individuals or asthmatics and where there is a positive score on the CSS-SHR questionnaire. Using this definition, the prevalence of SHR among a general population of adults is estimated at 6·3% (Johansson *et al.* 2006, Millqvist 2008).

Individuals with SHR often feel socially handicapped because of the risk of exposure to odours and chemicals in their daily lives. Some people have even been sick-listed or taken early retirement because of their respiratory tract problems (Millqvist *et al.* 1998, Millqvist 2000, Johansson *et al.* 2002). Studies of quality of life as measured using the Nottingham Health Profile questionnaire (NHP) have shown that individuals with SHR have a significantly reduced quality of life compared with the reference values and that this reduction does not change over 5 years (Ternesten-Hasséus *et al.* 2007). The NHP focuses on how symptoms and disease impact the patient's health, well-being and ability to function in daily life. It consists of two parts, the first of which is divided into categories such as pain, insomnia and social isolation. The second part contains questions about how the health problems impact the individual at work, when doing household chores, in their social life, in their family life and so on (Wiklund *et al.* 1988, Patrick & Deyo 1989). The purpose of the form is to enable the patient to clarify the effects of his/her disease (Millqvist *et al.* 2000).

One concern for individuals with SHR is that they sometimes find that their problems are not taken seriously;

consequently they feel misunderstood in their contacts with healthcare. It is important for their care that attention be paid to their problems. When individuals who are living with chronic asthma receive support from healthcare personnel, their options and ability to cope with their situations effectively on their own are enhanced (Koch *et al.* 2004). Healthcare personnel often have close contact with patients with chronic diseases and consequently need to have an understanding of and sensitivity to how these individuals experience their symptoms. Healthcare personnel must consider the social and emotional domains in the individual's life, as well as the physical symptoms (Kralik *et al.* 2005). There is still a lack of studies in which SHR sufferers describe their situations in their own words and therefore the purpose of this study has consequently been to describe how individuals with hypersensitivity to odours and chemicals handle their problems.

Methods

The study was conducted using a qualitative approach (Polit & Beck 2004). It is natural to employ a qualitative method when the intention is to let individuals describe their own situations. If one wishes to study how individuals experience their own problems in the life situation in which they find themselves, interviews offer an appropriate alternative for obtaining such information. The personal encounter in the interview may help make it possible to capture nuances and penetrate facades (Bäck 2003). Data are gathered with the help of recorded interviews based on open questions. Interviews are used as a means of understanding how people experience their world and to gain insight into their perceptions, experiences and emotions. The goal of the qualitative research interview must be to obtain nuanced descriptions of various qualitative aspects of the interviewee's life-world (Kvale 1997).

Ethical considerations

The study was designed according to Declaration of Helsinki (2000). Information about the study was provided to the interviewees both verbally and in writing. They were informed about their rights to decline to participate or withdraw at any time. The interviewees were informed that the recorded and transcribed interviews would be treated confidentially and that their anonymity would be preserved in the presentation of the findings. They gave their informed written consent to participate in the study. Ethical approval was sought and obtained from the Göteborg Regional Ethics Committee.

Data collection

Individuals were recruited from 'the Skövde population-based study,' a population-based epidemiological study in which 1900 individuals aged 20 and above were selected at random from the population register for Skövde municipality. Because the demographics of Skövde municipality correspond well with the demographics of Sweden as a whole, the results from 'the Skövde population-based study' are considered to be generalisable to the population of Sweden (Johansson *et al.* 2003, 2005). Of the 1387 individuals (73%) who entered the study, half (693) were later randomised, stratified by age and gender and asked to complete the CSS-SHR questionnaire. The 595 individuals (86%) who answered the questionnaire were divided into four groups with different sensitivities, based on their CSS-SHR scores. Of these individuals, 137 were then recruited, randomised and stratified by gender from the four groups. These individuals were invited to come in to inhale capsaicin (capsaicin provocation). Twelve individuals (eight women and four men) had positive capsaicin provocation tests as well as a positive CSS-SHR score. These 12 individuals were then asked to participate in this interview study. Of the 12, eight individuals were interviewed, five women and three men. Their average age was 58 (39–68). Three of the four individuals who chose to refrain did not wish to participate in another study and one individual could not be contacted.

A test interview was first conducted with a healthcare employee who had a pronounced sensitivity to odours and chemicals. The questions proved to work satisfactorily and so were not changed for the actual study. The interviews were conducted in the spring of 2005 and took the form of a conversation. A conversation brings knowledge forth (Rorty 1979). An interview can be described as an interaction between the interviewer and the interviewee (Kvale 1997). The individuals to be interviewed received written and verbal invitations to participate in the interviews. Six interviews were conducted at the researcher's office, while one took place in the interviewee's home and one was conducted in a quiet room in a reception area. The interviews began with a few introductory questions such as 'what work do you do?' and 'can you tell me what kind of odours or chemicals you cannot tolerate?' with the aim of creating a relaxed atmosphere and allowing the interviewee to become accustomed to the tape recorder (Polit & Beck 2004). The question that followed was open and broad: 'Can you tell me, in the greatest possible detail, how you experience your problems when you encounter something you cannot tolerate?'.

The responses then gave rise to follow-up questions, probing questions and specific questions in attempts to explicate and

clarify the situation and render the subsequent analysis more reliable (Kvale 1997). The interviews took between 20–40 minutes to conduct. The transcribed texts ran from four to nine pages in length, printed using line spacing of 1·5.

Analysis

A qualitative content analysis was chosen to analyse the interview data (Graneheim & Lundman 2004). The recorded interviews were transcribed verbatim, in correspondence with Linell's level II (1994), which means that the transcriptions reproduced all identifiable word occurrences, including repetitions. Sighs, laughter and extended pauses were also noted in the transcription. The interviews were printed out by the interviewer at the time of each interview. The analysis then continued as per Graneheim and Lundman (2004). First, the interviews were read through several times to grasp the purport of their contents. Meaningful units were then identified and coded. A meaningful unit, labelled with a code, allows us to think about the data in new and different ways (Graneheim & Lundman 2004). The codes were then clipped out and combined in different piles, based on content. Groups of codes were arranged and rearranged. The compilation process that followed yielded four themes that describe the interviewees' experiences of living with hypersensitivity to odours and chemicals. Each theme is described separately and the text is illustrated using quotations from the interviews. The quotation ends with (M) for a male interviewee and (F) for a female interviewee, respectively.

Results

Four themes emerged from the data analysis: 'Limitations in one's life situation', 'Lack of understanding from others', 'Concern that the symptoms will transition into a serious disease' and 'Disparagement of one's own personal experience'.

Limitations in one's life situation

Being hypersensitive to odours and chemicals could entail limitations in daily life and a need to monitor and control one's environment and the situations that might arise during the day. The interviewees described how they had developed strategies to allow them to cope in their daily lives. One common way of limiting themselves was to learn to live with their problems by avoiding those things that they could not tolerate:

> I simply can't enter that shop, my eyes smart …I have to leave immediately. (M)

Some interviewees who were bothered by tobacco smoke reported that the law in Sweden prohibiting tobacco smoking in restaurants and other places of business had been quite helpful to them:

> I try to avoid it and when it comes to smoke, things will hopefully be better now…but otherwise I'll have to leave the area, so to speak. (F)

Some interviewees avoided co-workers who used a perfume or cologne that made them feel ill. Some also found it necessary to avoid certain situations, which led to limitations in the job tasks that they could perform, as well as in the activities in which they could participate. Wall-to-wall carpeting at work could cause problems as well:

> We have someone who uses…it's the smell that makes me feel so bad and I avoid her ever since she got that perfume. (F)

> We have relaxation exercises in that room in the morning and it ended up with me leaving; I couldn't take part because we were supposed to lie down on the wall-to-wall carpet and my throat started to catch and I felt bad. (F)

When the problems first arose and it was difficult to know how to manage them, it was easy to spend too long in contact with the substance that was causing the symptoms. Because this led to various problems, the interviewees soon learnt how to avoid such situations. One strategy was to avoid certain shops where the substance that caused the symptoms was exposed in such a way that necessitated walking past it on the way to the checkout counter. Another way to avoid unfavourable settings was to avoid using public transport. Other passengers on buses and trains might smell strongly of smoke, or a perfume, with the result that a person who was made to feel ill by these substances had to either move or get off if he or she did not wish to feel ill. This made it difficult or impossible to go along on trips arranged at work if buses or trains were used as the means of transport. Similar problems could also arise on family holidays. The external environment, for example a hotel room with wall-to-wall carpet where smoking was allowed, could cause additional problems. One way to deal with an overnight trip could be to rent a room or cabin that one could personally clean and keep absolutely spotless:

> I have to move (if I take the bus)…it doesn't work out if they happen to sit next to me (people wearing perfume)…the only thing for it is to move, because it affects your breathing and everything. (M)

> I often clean when I get to a place that I have rented…start cleaning and make it clean is what I have to do, otherwise I can't stay there. (F)

Seven of the eight interviewees indicated that SHR limited their life situation.

Lack of understanding from other people

The feeling of being socially handicapped could be intensified by other people's lack of understanding about the content of the experience, despite the fact that sensitivity to odours and chemicals is common within the population. The inability to tolerate certain odours could seem peculiar and the interviewees were sometimes perceived as being whiners, or as being difficult:

You can be sitting at a meeting where people reek of strong perfume and an undertone of sweat. And it attracts a bit of attention when you have to inhale and all that and, well...I know that people have thought that I was being fussy…(F)

The same thing could happen in contacts with healthcare. As patients, some of the interviewees found that healthcare personnel had little or no knowledge that an odour could elicit severe symptoms in sensitive people. They frequently felt misunderstood and were sometimes told that if no signs of asthma or allergy were present, they had no grounds for complaint:

The staff come back from their breaks and smell of smoke and coffee and what-not and it's…I haven't told anyone that they're causing me any problems…you'd just look like a whiner. (F)

Several interviewees set limits for other people and in this way could create a functional daily life for themselves without experiencing severe symptoms. For example, it could be necessary to tell one's co-workers that the perfume or body lotion they were using had an odour that was causing problems. In some cases, it could be easier to communicate the fact that certain odours and chemicals needed to be avoided within one's immediate family. Another strategy was to get help from others in the vicinity when certain tasks were unavoidable:

And there was this one woman who had on a perfume that I couldn't tolerate and it was so heavy that I had to go out and I said to her…I had to because I couldn't work. (F)

She salved her hands with some cream and my head was heavy and I got an unpleasant sensation and I simply had to remove the odour…and then I asked her to wash her hands and I opened a window to get a breath of air. (F)

My husband doesn't use anything that's irritating to me right now…I usually go along and check things out before he buys them and very faint scents are ok. (F)

It's the same way with things that have to be painted with oil-based paint or such, I ask someone else to do it. (M)

Four of the interviewees had found that other people had a hard time understanding that a person may react to odours and chemicals.

Concern that the symptoms will transition into a serious disease

The most common symptoms upon exposure to certain odours and chemicals involve the upper respiratory tract, such as nasal congestion or irritation of the eyes or throat. Other individuals react with lower respiratory tract symptoms such as coughing, difficulty breathing and pressure across the chest. It is also common for people with SHR to experience general symptoms such as headache, tiredness and nausea. Some of the interviewees reported that they have another disease concomitant with their SHR and they will sometimes experience concerns and anxiety that the symptoms of SHR will transition over to the other disease:

When I get this feeling of huge discomfort, I have to get away at once and I will not breathe in, I simply don't want to inhale. (F)

Some of the interviewees suffered from migraines on occasion. When they got a headache and became nauseated by an odour they had encountered, they were greatly concerned that the headache would trigger a migraine attack that might last several days. Worries about being forced to stay in a situation could also increase the intensity of the symptoms:

The discomfort comes from being slightly nauseated and, to begin with…having a pressure headache. If I stop experiencing the odour, it goes away, but with a migraine…when that comes on you don't really know whether it will pass or keep on going, so you have that feeling of discomfort in that you fear it will trigger a proper migraine attack and you sort of associate the odours with the fear of getting a migraine attack. (F)

I don't get away from there and I feel like I'm starting to get a headache and that it's starting to get harder to breathe and I feel ill and…it just strengthens the feeling that you can't escape. (F)

Four interviewees reported experiences within this category.

Disparagement of one's own personal experience

One way that the interviewees managed their symptoms was to disparage them, both to themselves and to others. The reason might be that the symptoms seemed too trivial to

speak of or care about and that there was always someone who had it worse. To downplay or even deny one's symptoms could provide a way to be seen as being healthy. Some interviewees also believed that the symptoms that arose upon exposure to an odour or chemical represented a normal reaction and that everyone experienced similar symptoms when exposed. Some felt that ailments simply get worse as one ages and that their experiences were normal:

Actually I don't really have any major symptoms. (M)

But then you get to thinking that this may well have to do with getting older, that you'll experience a little of this...yes. (F)

Two interviewees disparaged their own symptom experiences in this way.

Discussion

One interesting finding of the study was that several of the interviewees felt that they had a hard time eliciting sympathy and understanding for their symptoms among their co-workers, during their free time and in contacts with healthcare. Might these individuals be having difficulty describing their symptoms? Symptoms are always asked about during contacts with healthcare and it may be that the healthcare personnel viewed the symptoms as being too vague to take seriously. This perceived lack of understanding could also be attributable to the staff's ignorance of how individuals with SHR experience their symptoms. Additionally, symptoms such as these cannot be verified using the blood tests or other objective tests on which healthcare personnel customarily rely. Nurses need to know about SHR and how patients cope with it in their day-to-day lives. The care that nurses provide can be improved if they gain knowledge about how patients such as the interviewees in this study themselves describe and experience their situations. Hansson Scherman (2002) observed in her study that individuals with asthma found that the knowledge they believed themselves to possess concerning their disease was difficult to communicate and explain, both to healthcare personnel and to the people in their daily surroundings. This finding was verified in the present study.

Reed Gibson *et al.* (1998) showed in her study of individuals with MCS that other people had negative attitudes towards those who were sensitive to chemicals, but that they also had poor or insufficient knowledge of just what that sensitivity entailed. If patients with pronounced sensitivity to odours and chemicals are to receive good care, healthcare personnel must improve their knowledge of this condition.

The results also show that the interviewees tried to avoid coming into contact with the substances they could not tolerate and that when they were successful they could generally function fairly well in their daily lives. Things worked out well for them if they could stay at home rather than going out into society. Outside of the home, it is far too easy to be confronted by strong aromatic products and by people who find it difficult to be considerate. Avoiding the substances, one cannot tolerate entails an active personal battle and this is also consistent with the principles of traditional medicine (Hansson Scherman 2002). As long as healthcare has no relief or cure to offer, avoidance is a good strategy for feeling good. The consequences that this has for the individual may, however, be major. A restricted social life can lower the quality of life considerably for many people.

It is important to obtain information about what happens when the symptoms of SHR arise. Several interviewees were concerned that the symptoms elicited, when they encountered odours and chemicals they could not tolerate would transition over to other diseases. Difficulty in breathing brought fears that an asthma attack might develop, or a pounding headache brought fears of transition to a migraine attack. In both cases, we are dealing with strong, albeit non-harmful, discomforts that the interviewees feared might turn into more serious diseases. Education and information can provide a means of coping with such fears. Patients with asthma-like symptoms who completed a problem-based educational program about their health experienced higher self-confidence, changed their views of themselves and their symptoms and also began using conscious coping strategies to manage their symptoms (Ringsberg *et al.* 2002).

Methodological considerations

The interviewees who participated in the present study were diagnosed using the criteria for SHR. Nevertheless, one of the interviewees denied her symptoms during the interview. The symptoms that did come to light in the interview were explained away by saying that 'everyone has problems with those sorts of substances' and 'it is just part of getting older'. Hansson Scherman (2002) found in her study of asthma patients that some of them believed they could make their condition go away by not paying it any attention in thought, word or deed. Some believed they could maintain control over their disease/health by considering themselves to be sick only when they personally felt that something was wrong with their bodies. Such explanatory models could potentially be used to explain this interviewee's denial of her symptoms. On the contrary, Kvale (1997) points out that certain individuals are more difficult to interview than others and

that a great deal will then depend upon the interviewer's motivational skills. It may be that the interviewer had difficulty motivating this interviewee to give interview responses that were rich in terms of experiencing symptoms. Qualitative researchers must ask themselves who would be an information-rich data source to maximise the understanding of the phenomenon studied (Polit & Beck 2004). The interviewees were selected after having participated in a population study. The selection is thus broad and deep, insofar as the interviewees had differing experiences of living with SHR.

There is always a risk of a certain degree of bias in the results, mainly because the interviewer is human and can thus influence the interviewees unconsciously (Bell 1995). One limitation of this study is that the interviewer had previously met all the interviewees in connection with the capsaicin provocation tests. As a result, they may have made an effort to please at the interviews. On the contrary, interviewees may feel more comfortable with an interviewer whom they have met previously. According to Kvale (1997), good interviews require expert knowledge about the subject. The interviewer in the present study had a good knowledge of the subject and was aware of her own preconceptions. A related issue is that an interviewer can attempt to elicit responses that confirm preconceptions or preformed opinions (Bell 1995). It is consequently important to listen to what the interviewee has to say, without letting preconceptions get in the way. The data from the interviews was translated from Swedish to English and some of the quotations used might be language-sensitive and for that reason more understandable in Sweden. Qualitative content analysis was used to analyse the collected material. Efforts have been made to clearly describe the research problem, the method and the various analytical steps to increase the reliability of the study (Polit & Beck 2004).

Contributions

Study design: CL, LM; data collection: CL; analysis: CL, LM and manuscript preparation: CL, LM.

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