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Patients’ experiences of living with superior canal dehiscence syndrome

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ABSTRACT

Objective: The study investigated how the symptoms of superior canal dehiscence syndrome (SCDS) affected patients in their daily life, and how patients coped with the disease.

Design: This was a qualitative study; semi-structured interviews were performed and analysed according to the systematic text condensation method.

Study sample: Twelve of 13 identified patients with SCDS in the county of Norrbotten, Sweden, were included in the study.

Results: Five main categories were created based on the patients’ experiences of living with SCDS: (1) Experiencing strange symptoms: One “new” symptom was identified – mental fatigue. (2) A restricted life socially, physically and at work: All patients experienced some extent of limitation in their daily life. (3) To accept and to protect oneself: All patients had developed strategies to protect their ears from noise. (4) Misunderstood in health care: The diagnosis was sometimes delayed several years due to lack of knowledge among healthcare workers. (5) Carefully considering treatment (surgery): Symptoms were weighed against the risk of side effects.

Conclusions: SCDS was rendered an invisible disability. In the present study, we identified mental fatigue as a symptom not previously considered in the literature.

INTRODUCTION

Superior canal dehiscence syndrome (SCDS) or Minor’s syndrome was first described in 1998 by Lloyd B. Minor and his colleagues (Minor et al. 1998). People with SCDS have an acquired (Nadgir et al. 2011; Park et al. 2015) dehiscence, unilateral or bilateral, in the temporal bone overlaying the superior semicircular canal of the inner ear. This results in a “third window” in addition to the round and the oval windows.

The clinical manifestations of SCDS include cochlear, vestibular or vestibulocochlear symptoms (Davey et al. 2015). Common cochlear or auditory symptoms are conductive hearing loss in spite of middle ear pathology, pulsatile and gaze-evoked tinnitus, autophonia, hyperacusis and the sensation of ear fullness (Davey et al. 2015; Niisten et al. 2014; Saliba et al. 2014). Common vestibular symptoms include chronic disequilibrium, dizziness and pressure- and/or sound-induced vertigo (Hennebert sign and Tullio phenomenon) (Chi, Ren, and Dai 2010; Davey et al. 2015; Minor, 2000). More symptoms are described in Table 2.

The diagnosis of SCDS is both clinical and radiologic, and it is important that both these investigations are positive, since radiologic methods alone seem to overestimate the prevalence of SCDS (Mehta et al. 2015). Other methods used for diagnosing and describing SCDS are audiometric tests – often showing an air-bone gap in the lower frequencies with a bone conduction threshold that sometimes can be lower than 0 dB hearing level (Chi, Ren, and Dai 2010), and cervical and ocular vestibulocochlear-evoked myogenic potential (cVEMP and oVEMP) thresholds (Mehta et al. 2015; Zuniga et al. 2013).

Regarding the treatment of SCDS, there are various options. Some patients are satisfied with information about the diagnosis without further treatment and in some cases insertion of a tube in the tympanic membrane has been used. In some cases, reinforcement of the round and oval windows could be an appropriate minimal invasive alternative (Nikkar-Esfahani, Whelan, and Banerjee 2013). Since Minor and co-workers (Minor et al. 1998) described the syndrome in 1998, various more advanced surgical techniques and surgical approaches have been developed. In general, the aim of these treatments is to seal the dehiscence. This can be done either by plugging the affected canal, or by reinforcement of the dehiscence letting the semicircular canal stay intact (Shaia and Diaz 2013). Surgical approaches vary from the original approach through the middle cranial fossa (Carey, Migliaccio, and Minor 2007) to more recent ones that include the transmastoid and transcanal (endaural) approaches (Banakis Hartl and Cass 2018; Zhao et al. 2012). Complications and side effects described after SCDS surgery are sensorineural hearing loss, facial palsy, tinnitus and balance problems.

SCDS is a disease with many symptoms, some of them making it difficult for these patients to participate in normal social life. Questionnaires such as the Dizziness Handicap Inventory (see Crane, Minor, and Carey 2008; Jung et al. 2015; Ossen et al. 2017) have been used to investigate the burden of symptoms of SCDS. A qualitative approach gives an opportunity to people affected by this relatively unknown syndrome to describe their experiences from their own perspective and in their own words, making it easier for new knowledge regarding symptoms and
their consequences to come forward. Such knowledge may be important in clinical encounters as well as for evaluating treatment. To the best of our knowledge, no qualitative studies have been performed within the SCDS patient group.

The aim of the present study was to use a qualitative method in order to investigate patients’ experiences of living with SCDS, their symptoms, their coping and their experiences of health care and treatment. By focusing on the patients’ own descriptions, one could get a picture of how this disease can affect patients suffering from SCDS and also maybe discover new symptoms not previously described.

**Material and methods**

One of the authors (A. S.), a specialist in audiology, identified and diagnosed 13 patients with SCDS in the County of Norrbotten, Sweden, between 2008 and 2015. All of the patients had typical symptoms and a positive computed tomography (CT) scan. In addition, cVEMP (Eclipse, Interacoustics) was performed and positive for all patients but one, who did not show up for the examination. cVEMP was regarded positive if the ratio of the amplitude between the ears was greater than 0.36. All patients were invited to participate in an interview study and those who accepted agreed to have a researcher (J. Œ.) review their medical charts from primary health care and ear, nose and throat (ENT) clinic visits. A flowchart of the participants is presented in Figure 1. The patients who had had surgery were interviewed 1–4 years after surgery and the patients who did not have surgery were interviewed 1–8 years after diagnosis.

The data collection consisted of semi-structured interviews. The interviews, all performed by the first author (J. Œ.), were digitally recorded and later transcribed verbatim. The interviews were carried out with the support of an interview guide (Supplementary Appendix 1) created by the authors regarding symptoms, consequences in daily life, coping strategies, diagnosis and treatment (Wengraf 2001). However, it was important to allow the participants to follow their own thoughts and associations during the interview so as to discover new knowledge and experiences. The order in which the questions were asked could therefore vary.

Systematic text condensation (STC) was the method chosen for the qualitative analysis (Malterud 2012). The main structure of STC consists of four steps: (1) reading through the entire material several times in order to gain a general impression and identify preliminary themes (code groups); (2) identifying meaning units and labelling them according to the themes (coding); (3) condensing the content of the meaning units within each theme/code group; and (4) synthesising the contents of the condensates as descriptions or concepts forming category headings. The coding and analysis were continuously discussed by three of the authors (J. Œ., K. T., A. F.). Having performed the coding, the content of the code groups was scrutinised, and in doing this, meaning units were divided into subgroups. Each subgroup was then transformed into a text condensate, in the form of a construed quotation in the first person that summarised the meaning of what was said in the quotations (Malterud 2012). A few authentic quotations were chosen to illuminate each text condensate. Thereafter, descriptive/analytical texts were created, based on the information provided within each subgroup as well as from all subgroups within a code. Finally, these texts were given names, or headings, appropriate to their content, as presented in the results.

The study was approved by the Regional Committee of Ethics, Umeå University, Sweden (dnr: 2015/261 31Œ).

**Results**

Thirteen patients were invited and 12 accepted, 7 women aged 51–72 years, and 5 men aged 43–67 years. Of these 12 patients, four had SCDS bilaterally. Three of them had had surgery on one side, and one on both sides. Eight patients had SCDS unilaterally, two of them had undergone surgery (Figure 1). Demographic data are visualised in Table 1. Findings in the qualitative analysis are presented under five category headings related to the aims of the article.

**Experiencing strange symptoms**

The participants gave expressive descriptions of their various symptoms. They all shared the experience of having “odd” symptoms, hard to explain to and understand for those around them. Most of these symptoms have previously been described in the literature. We have listed the participants’ report of symptoms in Table 2 and exemplified them with authentic quotations.

In addition, one symptom appeared that, to our knowledge, was not previously described or included in the symptomatology.
of SCDS. This was a feeling of overwhelming tiredness that was described as mental fatigue; a constant tiredness that did not go away no matter how much the patient slept. Six of the patients reported this symptom and some of the patients said that it was hard to make other people understand this tiredness. A man in his forties said:

I slept probably around 14–16 hours before the first operation. My wife became furious. Because there are no visible signs, you seem healthy. And you just can’t put into words how tired you really are.

For some patients, this tiredness or fatigue was paralysing, rendering a normal life almost impossible. Furthermore, some of the patients said that this tiredness/fatigue also led to other cognitive impairments such as difficulties in memory and learning.

A restricted life – socially, physically and at work

Suffering from SCDS had far-reaching consequences for many of the patients. Social limitations were of particular importance. For several, this led to alienation and the feeling of being asocial, and some reported feelings of depression. Ear discomfort because of loud sounds (hyperacusis) often resulted in abstinence from activities where there was a risk of being exposed to a lot of noise, such as having dinner with friends and family, music events, café and pub visits and shopping tours.

To go to a café or restaurant is also really hard for me, and then I have to wear earplugs, but it is still tough.

Autophony and conductive hyperacusis led to limitations in social interactions because it was difficult to participate in conversations without losing focus due to the disturbing sensation of one’s own voice being too loud. This also made these patients talk less, or more quietly.

All conversations I had were the shortest possible. It was just “yes, yay, yes…”. You answered with single syllables, because of the voice. When I talked the voice was so loud inside my head.

Difficulty in conversing at a dinner table when normal chewing sounded like chewing on crispbread all the time was described as another consequence. Autophony was also one of the symptoms that is difficult to make adjustments for in their work life, as one of the patients reported:

The louder I speak the noisier it gets in my own ear. And I have trouble assessing how loud I speak. So this becomes a handicap when I teach or give a lecture.

One patient could not go to the dentist because of non-tolerance of the drilling sound as this caused a sensation of getting hit with a hammer drill inside the head.

Balance issues presented problems in everyday life for about half of the patients. A few of them reported that they had lost their balance one or more times due to the sudden onset of vertigo that was often caused by pressure changes or exercise (Hennebert’s sign). These balance problems also led to difficulties in maintaining a good physique because the effort of training induced vertigo.

Most patients reported that, despite having SCDS, they managed to do their job even though some of the employers had had to make some environmental adjustments. Examples of such adjustments were sound isolation or creating an isolated workspace instead of letting the affected person work in a cubicle.

Table 2. Symptoms that have been described in previous literature with exemplifying authentic patient quotations from the present study.

<table>
<thead>
<tr>
<th>Cochlear symptoms</th>
<th>Symptom</th>
<th>Meaning</th>
<th>Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing loss</td>
<td>Partial or total inability to hear</td>
<td>I hear badly. Probably my biggest issue is that I hear badly, so I have to ask again. And sometimes I wake up because of the tinnitus. But then after a while I realize &quot;oh no it’s not a car alarm, it’s in my head&quot;, and then it’s no fun.</td>
<td></td>
</tr>
<tr>
<td>Tinnitus</td>
<td>A ringing or similar sensation of sound in the ears</td>
<td>It feels blocked up, like if you are in an on the way down. And you want to blow, but nothing happens. And when I spoke it felt as if I was inside a bell jar and the voice was outside. Like now when I’m speaking with you, I hear myself as if I’m in a can. Somewhat like a broken radio...</td>
<td></td>
</tr>
<tr>
<td>Aural fullness</td>
<td>A sensation that the ears feel blocked up or stuffy</td>
<td>I feel as if someone is shouting right into my brain. I felt like I had my heart in my ear. … when you walked on gravel it felt as if you had your head in a bag of chips. And in the same way when you scratch, especially against the head, the sound is amplified. … you know what? When I move my eyes I hear it inside my head.</td>
<td></td>
</tr>
<tr>
<td>Autophony</td>
<td>To hear one’s own voice as changed and too loud</td>
<td>I felt almost like that game when you spin around a stick and someone tells you to go in a certain direction, and you try to, but you can only stagger. … one time at work while sitting in a meeting there was a fire truck with sirens passing by, and even though I sat down (ohhh) it started to spin in my head. So I gathered my strength and then I blew through both nostrils, … and I ended up in a centrifuge vertigo. I fell down to the floor… It was when I reached my nose and pinched and blew that the centrifuge stopped.</td>
<td></td>
</tr>
<tr>
<td>Cochlear hyperacusis</td>
<td>Sensitiveness to normal sound, causing pain and/or discomfort in the head</td>
<td>To hear sounds that are &quot;conducted&quot; and amplified throughout the body</td>
<td></td>
</tr>
<tr>
<td>Conductive hyperacusis</td>
<td>To hear sounds that are &quot;conducted&quot; and amplified throughout the body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vestibular symptoms</td>
<td>Chronic disequilibrium</td>
<td>A general sensation of lack of balance</td>
<td>I felt almost like that game when you spin around a stick and someone tells you to go in a certain direction, and you try to, but you can only stagger. … one time at work while sitting in a meeting there was a fire truck with sirens passing by, and even though I sat down (ohhh) it started to spin in my head. So I gathered my strength and then I blew through both nostrils, … and I ended up in a centrifuge vertigo. I fell down to the floor… It was when I reached my nose and pinched and blew that the centrifuge stopped.</td>
</tr>
<tr>
<td>Tulio phenomenon</td>
<td>Vertigo, nystagmus and oscillopsia induced by sound*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hennebert sign</td>
<td>Vertigo and/or nystagmus induced by pressure changes*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The meaning column is the author’s explanations for the symptoms found in the literature.

A few patients were affected to such an extent by SCDS that they had to quit their jobs. This happened after several attempts of redeployment and vocational training, and was experienced as very sad and traumatic.

To accept, and to protect oneself

The patients had developed various strategies to cope with their disease and symptoms. One way was to talk about it, explaining to people, for example, why they were struggling with their hearing.

If I join larger groups I might say “well I have some trouble with my ear so if I don’t hear, it’s not because I am nonchalant or anything…”

Others had chosen the opposite strategy, not to talk much about it. According to these patients it was very much about attitude, and about the decision not to let the disease take too much energy. They struggled to make everyday life run as smoothly as possible, even if this forced them to abstain from some things. Furthermore, while some symptoms tended to increase over time, many patients pointed out that some symptoms actually eased as they got used to them and learned to live with them.

Yes, it has been really tough. Really tough. But now I can feel that it’s easier. It’s all about acceptance. That the situation is as it is, and that I have to make the best of it. But no, it has not been easy.

The most important “practical” coping strategy among the patients was to protect their ears. This was most often accomplished by using different kinds of earplugs. Although sounds coming from inside of the body became louder, many patients pointed out that some symptoms actually eased as they got used to them and learned to live with them.

Going into shops where they play music is difficult. It is painful. Usually I put something in my ears, but some places I have to leave – sometimes I have to turn around already at the door. If I go to the gym, I must have my ear plugs – otherwise it would be impossible to stay there.

A problem with using earplugs, though, was that it became harder to interact with other people; this was experienced as a limitation. Also, frequent usage of earplugs led to increased sensitiveness to sounds when not using earplugs.

Another way of protecting the ears was to eliminate possible upcoming loud sounds, for example, by reaching to a closing door before it slammed, pulling in the leash before the dog barked or positioning the head when talking to people so that the sick ear pointed away from the voices.

Yes, all the time. No matter what you do. If the door slams… It is like that all the time. But I am so used to it that I often parry automatically when I can – I think: Now I have to grab the door before it closes.

These types of manoeuvres tended to come naturally without thinking.

Misunderstood in health care

Most of the patients went to see a doctor in primary care or in occupational health care when the initial symptoms of SCDS appeared. A common experience was that very few of the general practitioners or company physicians understood that the symptoms arose from SCDS. Common explanations were “water in the middle ear”, thus urging the patient to do Valsalva manoeuvres and to use nasal spray with cortisone. Other patients were informed that the symptoms derived from the neck, from stress or from high or low blood pressure. Many patients felt misunderstood and trivialised, which contributed to a delay of the correct diagnosis for several months or even years.

I got scared because it was so unpleasant. So eventually I called my health care center and the answer I got was: “when you get older you may get these kinds of problems”.

According to the primary health care records, the ear-related symptoms were often interpreted by the general practitioners as caused by secretory otitis media or plugs of earwax. The feeling of disequilibrium and vertigo was often interpreted as due to either high or low blood pressure levels, anxiety, or problems deriving from the shoulders and neck.

And they believed it was the blood pressure, so I measured my blood pressure, at first twice a week and later on once a week, but everything was fine. I had good blood pressure, so it couldn’t… Then they thought it came from an episode of having a common cold, but it never ceased.

After one or two visits most of the patients had been referred to specialist care. Some of them, however, “got stuck” in primary care, which entailed regular visits to a doctor and/or to a physiotherapist for several months and in some case for years before being put in contact with an ENT specialist. It was obvious that the tuning fork test (a tuning fork is placed against the malleoli or knee and is heard in the ear) was never performed (at least not documented) in the primary care. In none of the referrals from, the primary care was the suspicion of SCDS expressed; this further stresses that SCDS is still not a well-known diagnosis.

Getting a diagnosis was of great value. The experience of having symptoms that were strange, diffuse and hard to explain, had not become easier when they were told that “everything looked fine” inside their ear. Several of the patients had linked their symptoms to having a brain tumour or had thought they were becoming mentally ill, which was quite worrisome. When they received the diagnosis they felt a substantial relief, both in the sense of restoration – I told you it was something wrong with my ear – but also a confirmation that it was not a brain tumour, or that they were not about to go insane.

If I had not known this (the diagnosis) I’m not sure I would have managed… I think I would have jumped into the lake. Do you understand? It’s a shame if there are people out there who don’t know what they have, I’ll tell you that.

Having received the diagnosis also made it easier for the patients to relate to their symptoms and to accept the disease. It also became easier to talk about the disease and to explain to people in their environment why they felt as they did.

Carefully considering treatment (surgery)

Six of the 12 patients had undergone some type of surgery due to SCDS (Table 3). Of these, four had SCDS bilaterally. One of these four had surgery on both sides and was totally satisfied with the results with no remaining symptoms. The other three bilateral SCDS patients had surgery on one side, but had developed new symptoms from the other ear. Of the two patients with unilateral SCDS, one had a good result on the SCDS symptoms, but unfortunately had tinnitus as a side effect of the surgery. The other patient underwent a minimal invasive operation, where the round and oval windows were reinforced with fascia, but this had no effect at all on the SCDS symptoms.
All the patients in our study had carefully considered treatment, weighing the burden of symptoms versus the risks of side effects.

*He said that the operation was not completely free of risk. They would go in and cut behind my ear. But I found it so tough that I chose to do it anyway.*

Almost all of those who underwent surgery did so because the burden of symptoms was heavy and they felt they had no other choice. The possibility of getting some kind of relief outweighed the risks of surgery.

*I was more or less confined to bed at home, but it worked as an incentive. I felt I had to do something…*

The patients thus adopted a wait-and-see attitude at first, but when the disease burden became unbearable the decision for surgery was taken.

**Discussion**

In the present study, we investigated symptoms, impact on daily life, coping strategies and experiences of health care and treatment of patients with SCDS. The symptoms already described in the literature regarding SCDS disease (Minor 2000, 2005; Saliba et al. 2014) were confirmed in the present study; in addition, however, several patients described an experience of mental fatigue (=abnormal tiredness) leading to cognitive impairment. Wackym et al. (2016) reported improved cognitive performance after SCDS surgery, but this study did not make the connection between memory difficulties and excessive tiredness. Ward, Carey, and Minor (2017) and Bigelow and Agrawal (2015) also talk about “brain fog” as a cognitive impairment of SCDS patients, but they do not mention tiredness or fatigue as a possible reason for this. Ossen et al. (2017) made a systematic literature review regarding outcome measures after SCDS surgery found on different validated questionnaires and objective measures, such as VEMP and audiometry, but excessive tiredness is not mentioned as a symptom that could be of importance among patients with SCDS. To our knowledge, this tiredness or mental fatigue has not been previously described as a prominent symptom in SCDS patients. Further studies are needed to investigate the extent of such symptoms in this patient group, a symptom that about half of the participants in the study reported in the interviews. One explanation for SCDS having mental fatigue could be the constant stress to the brain from hearing loud sounds from within or outside the body and also the constant alertness from trying to avoid exposure to sound. Such distress has also been reported in patients with severe tinnitus (Hasson et al. 2011). In order to verify and quantify the presence of mental fatigue among SCDS patients, it would be important to include this question in future questionnaires.

SCDS was described as an invisible handicap by the patients themselves, sometimes very disabling for the affected person. The patients reported different attitudes as to how to cope with their situation; these attitudes might also be influenced by the degree of symptoms. We consider it important for health care workers to ask each individual patient with SCDS about her/his symptoms as well as coping strategies in order to provide appropriate support and/or initiate and evaluate interventions.

It was very valuable for the patients to receive the correct diagnosis since they had often been misunderstood by the health care, in some cases for many years, causing feelings of abandonment and worry. This underlines the importance for health care workers to be aware of this patient group. This should not be regarded as a difficult goal as it is often sufficient to use a few questions and simple examinations, such as the Weber test, a tuning fork to the malleolus and pneumatic otoscopy, to suspect the diagnosis (Chi, Ren, and Dai 2010; Minor 2000).

Regarding the outcome of surgical treatment, the results spanned from complete recovery to no relief at all. These results are probably due to the different surgery methods used and also to the progress of the disease from one affected ear to involvement of both ears; this has also been recorded by other groups (Agrawal et al. 2012). The patient operated with occlusion of the round window did not show any beneficial effect. On the other hand, the patient operated on with the plugging method on both ears showed a complete recovery from the disease. Since there are still several surgical methods to deal with this condition (Crane et al. 2010; Nikkar-Esfahani, Whelan, and Banerjee 2013; Shaia and Diaz 2013; Zhao et al. 2012), it seems that the surgery methods need to be better evaluated, as well as establishing the proper indications for the different treatment methods available.

The patients in the present study had often googled on the Internet about different surgery methods and possible side effects and therefore often adopted a wait-and-see attitude towards surgery unless the symptoms became unbearable. Since SCDS is a relatively new syndrome there is not a lot of information regarding the progression of the disease if not operated on. In our material, we found that most of the patients became worse, rather than better, which is also reported by Ward, Carey, and Minor (2017). This would imply that patients with this disease could not hope for a spontaneous recovery. On the other hand, patients living with SCDS for decades perhaps come to a state of acceptance.

One limitation of the present study could be that some of the patients with successful surgery may have forgotten some of the symptoms that they had before surgery as some of the patients were interviewed up to 4 years after the surgery.

The strength of our study is the qualitative approach in which we were able to focus on self-reported symptoms of patients with SCDS with possibilities of finding new symptoms not present in the different questionnaires used for evaluation of SCDS patients. We thus believe that health care providers should ask SCDS patients more about tiredness and coping strategies in order to get a better pre- and post-operative evaluation.

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**Table 3. Subjective effects of surgery.**

<table>
<thead>
<tr>
<th>Pat. no.</th>
<th>Uni- or bilateral SCDS</th>
<th>Surgical method</th>
<th>Year of surgery</th>
<th>Subjective effect of surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bilateral</td>
<td>Transmastoid plugging on one side</td>
<td>2014</td>
<td>Residual symptoms</td>
</tr>
<tr>
<td>3</td>
<td>Bilateral</td>
<td>Transmastoid resurfacing on one side</td>
<td>2011</td>
<td>Good at first, now recurring symptoms</td>
</tr>
<tr>
<td>4</td>
<td>Bilateral</td>
<td>Middle fossa, resurfacing on both sides</td>
<td>2010 and 2014</td>
<td>Completely satisfied.</td>
</tr>
<tr>
<td>6</td>
<td>Unilateral</td>
<td>Reinforcement of the round and oval windows</td>
<td>2014</td>
<td>No effect</td>
</tr>
<tr>
<td>9</td>
<td>Bilateral</td>
<td>Transmastoid resurfacing on one side</td>
<td>2013</td>
<td>Good at first, now contralateral symptoms</td>
</tr>
<tr>
<td>11</td>
<td>Unilateral</td>
<td>Transmastoid plugging on one side</td>
<td>2007</td>
<td>Good, tinnitus postoperatively</td>
</tr>
</tbody>
</table>

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Conclusions

There was large variation in how the patients experienced their SCDS symptoms and how much they were affected in their daily lives. Nevertheless, it was evidenced that SCDS could constitute an invisible handicap that caused severe disability in some patients. Autophony and sound hypersensitivity were prominent symptoms in many. Mental fatigue as a symptom had not been paid attention to in connection with SCDS; we suggest that it be included in future studies.

Disclosure statement

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