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Self-reported cognitive impairment and daily life functioning 7–12 years after seeking care for stress-related exhaustion

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The overall aim of this study was to investigate self-reported cognitive difficulties, daily life activities, and health/sleep factors in former patients with exhaustion disorder (ED) who still fulfill the clinical criteria for exhaustion 7–12 years after seeking care. The Sahlgrenska Self-reported Cognitive Impairment Questionnaire (SASCI-Q) was used to measure cognitive difficulties, daily life activities, and health/sleep factors. Three groups were compared: previous patients still judged to be clinically exhausted seven years or more after seeking care (n = 51); previous patients considered clinically recovered (n = 98); and healthy controls (n = 50). Patients who still fulfilled the diagnostic criteria for ED reported widespread problems related to cognition, fatigue, and daily life functioning compared to the clinically recovered group. Furthermore, despite no longer fulfilling the clinical criteria, the recovered patients still reported more problems related to cognitive functioning and fatigue compared to healthy controls. Thus, this group appeared intermediary between the non-recovered group and healthy controls regarding self-reported cognitive functioning. To conclude, ED may have considerable negative long-term effects, and it is possible that some of these residual symptoms, particularly the cognitive problems and persistent fatigue, are permanent in some patients. Preventive measures should be the primary focus for all stakeholders, since the consequences of stress-related mental health problems seem to be extensive and long-lasting.

Key words: Burnout, cognition, exhaustion disorder, perceived health, self-report, stress.

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INTRODUCTION

Stress-related mental health problems have been the fastest growing cause of sick leave in Sweden since 2010, according to the Swedish Social Insurance Agency (Försäkringskassan, 2020). The diagnosis of exhaustion disorder (ED) (F43.8) is included in the diagnostic group F43, “Reaction to severe stress, and adjustment disorders”, in the Swedish version of ICD-10 (World Health Organization, 1992). This criteria-based diagnosis is applicable in clinical practice to describe patients seeking care for symptoms of exhaustion due to identifiable stress exposure lasting for at least 6 months. ED overlaps with the concept of clinical burnout (Grossi, Perski, Osika & Savic, 2015) and has substantial comorbidity with depression and anxiety (Glise, Ahlborg & Jonsdottir, 2012).

Many patients with exhaustion seem to struggle with a slow pace of recovery. Several studies have shown that even two to three years after seeking care, around one third of patients with exhaustion/clinical burnout still report mental and/or physical fatigue and <exhaustion (Glise et al., 2012; Hatanen et al., 2009; Stenlund, Nordin & Jarvholm, 2012). This was confirmed in our recent study where we found that as many as one third of patients were clinically judged to have exhaustion seven years after seeking care (Glise, Wiegnner & Jonsdottir, 2020). In studies using cognitive testing, stress-related exhaustion has been associated with cognitive impairment, mainly related to speed, attention, working memory, and executive function (Eksildsen, Fentz, Andersen, Pedersen, Kristensen & Andersen, 2017; Jonsdottir, Nordlund, Ellbin et al., 2013; Ohman, Nordin, Bergdahl, Slunga Birgander & Stigsdotter Neely, 2007; Österberg, Karlson & Hansen, 2009; Sandstrom, Rhodon, Lundberg, Olsson & Nyberg, 2005). Previous studies have similarly shown cognitive impairments in such patients up to three years after seeking care, mainly in terms of working memory and attention (Eksildsen et al., 2017; Jonsdottir et al., 2013; Oosterholt, Maes, Van der Linden, Verbraak & Komper, 2016; Österberg et al., 2009).

The slow recovery pace seen among patients with ED raises the question of how well these individuals are functioning cognitively in their daily lives, years after seeking care, particularly those who still fulfill the criteria for ED more than seven years after seeking care. The majority of these individuals are not on sick leave and thus, are likely expected to perform normally at work and participate in everyday activities, given that such a long time has passed since they first sought care.

The overall aim of this study was to investigate self-reported cognitive difficulties, daily life activities, and health/sleep factors among individuals 7–12 years after receiving an ED diagnosis. We aimed to address the following questions:

- Do self-reported cognition, daily life activities, and health/sleep differ between patients who still fulfill the clinical criteria for ED after 7–12 years and patients who no longer fulfill these criteria?
- Do self-reported cognition, daily life activities, and health/sleep differ between former ED patients who no longer fulfill the
criteria for ED and healthy controls, 7–12 years after the patients sought care.

METHODS

Study design and participants

This study was a part of a major longitudinal study conducted at the Institute for Stress Medicine, a specialist outpatient clinic for patients with ED in Gothenburg, Sweden.

Former patients with exhaustion disorder (ED). The patients were initially referred to the clinic from primary care units or occupational health care centres. All patients included in the study were initially clinically assessed by a specialist physician at the clinic to judge if they fulfill the criteria for ED. The diagnostic procedure for ED has been previously described in detail (Jonsdottir, Hagg, Glise & Ekman, 2009). All patients included had been on sick leave for at most six months before they first sought care. The initial diagnostic procedure excluded patients with generalized pain, fibromyalgia, chronic fatigue syndrome/myalgic encephalomyelitis, thyroid disease, vitamin B12 deficiency, obesity, alcohol/drug addiction, psychiatric illness other than depression and anxiety, and other somatic disease that could explain fatigue. The mean duration of treatment at the clinic was approximately 18 months. The treatment regime has previously been described in detail (Glise et al., 2012; Glise, Ahlborg & Jonsdottir, 2014).

Following their treatment at the clinic, the patients were invited to participate in several follow-ups and asked to fill in a battery of questionnaires including questions about mental and somatic symptoms. Of the patients admitted to the specialist unit for treatment, 506 were followed up over time via register data. In connection to the seven-year follow-up, all patients who had passed this time point (353 of 506 patients) were asked to participate in a clinical assessment (see Fig. 1 for flow chart) involving a doctor’s visit to further assess residual stress-related exhaustion and completion of a number of assessment scales. The seven-year limit was chosen partly because long-term follow-ups are needed and partly because this follow-up offered enough patients to analyze remaining symptoms.

Of the 163 patients (46% of 353) who chose to participate in this clinical follow-up, 51 (31%) were judged to still fulfill the ED criteria and 99 (61%) were judged to no longer fulfill the criteria (Glise et al., 2020); the remaining 13 were assessed to be exhausted due to other reasons such as alcohol abuse or hypothyroidism, and were not included in the study. One patient who did not fulfill the ED criteria had missing data on the Sahlgrenska Self-reported Cognitive Impairment Questionnaire (SASCI-Q) and was also excluded. Thus, 149 patients were finally included in the current study: 116 women (78%) and 33 men (22%), comprising 51 who finally included in the study population, based on clinical experience. We categorized the items into themes that were considered relevant for the current study population, based on clinical experience. We categorized the cognition-related items into six themes: communicating with others (3 items), feeling cognitively insecure and making mistakes (7 items), getting comments from others on one’s functioning (4 items), learning and memory (7 items), using memory aids (3 items), and general/executive cognitive function (5 items). Thus, themes were not chosen to match cognitive domains, but rather to reflect areas relevant for everyday life. The items on daily life activities and health and sleep were not categorized into other themes.

Items referring to previous function (e.g. 25 years ago) were excluded from analysis in the current study, due to the participants varying ages. The SASCI-Q scale’s measures of internal consistency reliability and convergent validity is high, as reported in a previous study (Eckerstrom et al., 2013).

Hospital anxiety and depression scale (HADS). The Hospital Anxiety and Depression Scale (HADS) was used to assess self-reported symptoms of depression and anxiety in the patients (Zigmond & Snaith, 1983). This scale consists of two subscales, HADS anxiety and HADS depression, each with seven statements responded to on a four-grade Likert scale from 0 to 3. The item scores are summarized within each subscale, with scores ranging from 0 to 21 points. A score of 0–7 indicates a non-case, 8–10 indicates a possible case, and 11–21 indicates a case of depression or anxiety (5). In this study, a score > 10 was considered to define symptoms indicating probable depression and anxiety respectively. HADS has been found to have satisfactory reliability and validity (6), and has also been shown to be sensitive in reflecting changes over time in response to different interventions.

Ethics

The study was approved by the regional ethical review board in Gothenburg, Sweden, (ref: 688-15). All participants gave their written consent form before entering the study.

Data handling and statistical analysis

The responses for the cognition-related SASCI-Q items were dichotomized into negative versus positive outcomes. The cut-off for a positive outcome varied for the individual questions (see the classification in the tables in the results section). One SASCI-Q item contains a qualitative response (If any, which of the following difficulties has affected your sense of well-being the most, in the last month?) and was therefore analyzed.

Healthy controls. The results from the SASCI-Q instrument were compared with data from a healthy control group consisting of 50 individuals aged 50–79 years who were recruited within the Gothenburg MCI study, a dementia research project at the Sahlgrenska University Hospital memory clinic (Wallin, Nordlund, Jonsson et al., 2016). Healthy controls were primarily recruited from senior citizens’ organisations. To be eligible for inclusion, the controls should not experience or exhibit any cognitive decline at the time of inclusion in the study and should have a Mini-Mental State Exam score of > 26. Exclusion criteria were any severe somatic or psychiatric disease.

Measurements

Self-reported cognitive difficulties. We used the SASCI-Q (Eckerstrom et al., 2013) to measure subjective cognitive impairment. SASCI-Q is a self-report questionnaire focusing on difficulties in daily life related to cognitive impairment, and including questions on daily life activities, health, and sleep. It was originally developed and validated in a memory clinic setting based on interviews with patients and relatives of patients seeking care due to cognitive difficulties. In the present study, we analyzed 46 items from the SASCI-Q: thirty items related to cognition, nine items related to daily life activities, and seven items related to health and sleep. Specialized clinical psychologists (authors SE and ME) categorized the items into themes that were considered relevant for the current study population, based on clinical experience. We categorized the cognition-related items into six themes: communicating with others (3 items), feeling cognitively insecure and making mistakes (7 items), getting comments from others on one’s functioning (4 items), learning and memory (7 items), using memory aids (3 items), and general/executive cognitive function (5 items). Thus, themes were not chosen to match cognitive domains, but rather to reflect areas relevant for everyday life. The items on daily life activities and health and sleep were not categorized into other themes.

Items referring to previous function (e.g. 25 years ago) were excluded from analysis in the current study, due to the participants varying ages. The SASCI-Q scale’s measures of internal consistency reliability and convergent validity is high, as reported in a previous study (Eckerstrom et al., 2013).

Drop-out analysis. Data for the patient group were collected between February 2016 and October 2017. A drop-out analysis comparing participants (n = 149) with those who were eligible but did not participate (n = 204) (Fig. 1) showed that the proportion of men was significantly lower among participants than among non-participants (22% vs. 33%, p = 0.022). Participants were also significantly older than non-participants at the time point for the study: 52 years (SD 9.8) versus 50 years (SD 9.2) (p = 0.007). Burden of symptoms (burnout, depression, and anxiety) measured at the time of initially seeking care did not differ between non-participants and participants and neither did comorbid clinical diagnosis regarding depression and anxiety differ between the groups. Furthermore, civil status and educational level did not differ between participants and non-participants (data not shown).
A composite measure was calculated for themes containing two or more items, showing percentage of individuals classified as scoring a positive outcome for at least one item within respective theme.

Group differences regarding demographic variables (age, sex, years of education, time to follow-up) were analyzed using a chi-square test or an independent samples t-test as appropriate. Group differences for the dichotomized SASCI-Q items were analyzed using a chi-square test. Due to difference in age between EDrec and HC, the analysis between these groups where recalculated stratifying for age. Thus, all patients within the range from the youngest healthy control (54 years) and the oldest patient (age 71 years) were included in these sub-analysis (n=49 (EDrec), n=27 (HC)). The mean age for the groups in the sub-analysis was 61 years (SD 5.3) for the EDrec group and 64 years (SD 5.3) for the HC group.

The level of significance for all analyses was set at \( p < 0.05 \). Statistical analyses were performed using version 24 of IBM SPSS Statistics.

RESULTS

There were no significant differences between ED and EDrec regarding age, sex, or time between baseline and follow-up (mean: 9.4 years; SD: 1.6; Table 1). Individuals in the ED group reported a higher educational level (mean: 16.7 years; SD: 3.0) than the EDrec group (mean: 15.5 years; SD: 2.8) \( (p = 0.02) \).

Healthy controls were significantly older compared to the EDrec group (mean: 69.6 years; SD: 7.4) compared to (mean:...
52.9 years; SD: 9.8) \( p < 0.001 \) and reported lower educational level (Table 1).

**Self-reported cognitive symptoms and daily functioning 7 years after seeking care for exhaustion disorder**

**Comparison between patients who were still clinically exhausted (ED) and patients judged to be recovered (EDrec).** Individuals still fulfilling the criteria for ED reported significantly more cognitive difficulties than those who had recovered, for all six composite themes (Table 2 and Fig. 2a). As many as 96% of the ED group reported difficulties related to learning and memory and difficulties related to general/executive cognitive function compared to 53% and 40% respectively among the EDrec group.

Five out of six themes from the daily life activities category differed significantly between the ED and EDrec groups (Table 3 and Fig. 2b). For instance, among the ED group, majority of the group (71%) reported that they managed to carry out only half or less than half of the things that they planned to do, while the corresponding percentage among the EDrec group was 18%. Being physically active was the only theme that did not differ between the groups.

The results from the health and sleep categories are shown in Table 4 and Fig. 2c, showing significant difference between ED and EDrec on all items except for the item “slept 6 hours or less, on average per night” that did not differ between the groups. For instance, 86% of the ED patients reported that they felt tired during the day, for half of the days or more compared to 37% of the EDrec group.

**Comparison between recovered patients (EDrec) and healthy controls.** Individuals in the EDrec group reported significantly more cognitive difficulties compared to healthy controls for all six cognitive themes (Table 2 and Fig. 2a). When analyzing only age groups 54–71 years, all themes remained significant between the groups, showing similar pattern as for the total group, except for the theme “getting comments from others about my functioning” that was no longer significant (27% among the ED group and 13% among the EDrec, \( p = 0.115 \)).

Three items concerning daily life activities differed between the EDrec group and the healthy controls, with the EDrec participants reporting less frequent reading, less engagement in social activities, and more difficulties with carrying out planned tasks, compared to healthy controls. Physical exercise, engaging in leisure and cultural activities, and watching TV did not differ between the groups (Table 3 and Fig. 2b). However, when comparing similar age groups (54–71 years) no significant differences were seen for patients and controls of similar age regarding any items concerning daily activity.

For the health and sleep categories, there was a significant difference for two items. EDrec participants reported more strain or stress compared to healthy controls, but only concerning any strain or stress, and not for daily strain or stress. EDrec participants also reported feeling tired during the day more often than healthy controls (Fig. 2c). When comparing similar age groups (54–71 years), experiencing strain did not differ significantly between the groups, whereas, “feeling tired during the day” remained significant (49% among the EDrec and 19% among the HC).

Radar charts (Figs. 2a–c) were created to summarise the pattern regarding cognition (Fig. 2a), daily life activities (Fig. 2b), and health/sleep (Fig. 2c) for all three groups of participants.

**Sub-analysis considering affective symptoms.** In a sub-analysis addressing the influence of affective symptoms, we excluded persons in the ED and EDrec groups who scored above the cutoff on the HADS scales for anxiety (excluded: ED, \( n = 15 \); EDrec, \( n = 8 \)) or depression (excluded: ED, \( n = 11 \); EDrec, \( n = 1 \)). Regarding cognition, the same six themes still differed significantly between the ED and EDrec groups (data not shown), and the pattern of differences between the EDrec group and controls also remained similar except for general/executive functions, which no longer differed between the groups. The results regarding daily life activities did not change. Finally, for the health/sleep questions, the differences between the ED and EDrec groups were no longer significant (experiencing daily strain or stress, and sleeping 9 hours or more), while the results did not change for the comparison between the EDrec group and healthy controls.

**DISCUSSION**

In this study, we investigated subjective perception of cognitive function and daily life activities in patients diagnosed with
Table 2. Self-reported everyday cognitive functioning during the last month measured with SASCI-Q. A composite measure was calculated for respective theme, showing percentage of individuals classified as scoring a positive outcome (i.e. reporting difficulties) for at least one item within respective theme.

| Themes and items from SASCI-Q | ED (n = 51) | EDrec (n = 98) | HC (n = 50) | ED vs EDrec, $\chi^2$ | EDrec vs HC, $\chi^2$ |
|-------------------------------|------------|---------------|------------|-----------------------|----------------------|
| N% N% N% Value df p           |            |               |            |                       |                      |
| Difficulties related to communicating with others – composite measure | 29 57 38 39 7 14 4.43 1 0.035 | 9.60 1 0.002 |
| Difficulties finding words that you usually know | 28 55 36 37 7 14 |
| Difficulties completing your sentences | 19 37 17 17 3 6 |
| ‘Lost the thread’ when you were talking | 11 22 5 5 0 0 |
| Feeling cognitively insecure and making mistakes – composite measure | 39 77 47 48 4 8 11.17 1 0.001 23.41 1 <0.001 |
| Felt uncertain about what you have said or not said | 16 31 20 20 0 0 |
| Felt uncertain about what others have said or not said | 24 47 21 21 2 4 |
| Forgot to buy a grocery even though using list | 6 12 6 6 0 0 |
| Looked for something you misplaced | 19 37 13 13 0 0 |
| Worried about your memory functions | 17 33 12 12 2 4 |
| Been mistaken about the right weekday | 7 14 8 8 0 0 |
| Had the feeling that you planned to do something, without remembering what it was | 26 51 23 24 0 0 |
| Getting comments from others about my functioning– composite measure | 27 53 31 32 5 10 6.40 1 0.011 8.42 1 0.004 |
| Someone else said that you said something you can’t remember saying | 18 35 22 22 3 6 |
| Someone else said that you did something you can’t remember doing | 7 14 9 9 1 2 |
| Someone else said or implied that you have a poor memory | 12 24 7 7 0 0 |
| Someone else reminded you about something | 17 33 18 18 3 6 |
| Difficulties with learning and memory – composite measure | 49 96 52 53 11 22 28.42 1 <0.001 13.07 1 <0.001 |
| Difficulties remembering people’s names | 36 71 37 38 8 17 |
| Difficulties remembering what you have read | 26 51 24 25 0 0 |
| Difficulties remembering episodes of last week’s TV-show | 14 28 3 3 1 2 |
| Difficulties learning new things, even things that interest you | 17 33 12 12 2 4 |
| Difficulties learning phone numbers by heart | 33 65 23 25 5 10 |
| Experienced memory problems | 22 43 18 19 2 4 |
| Difficulties remembering facts that you usually know | 25 49 21 21 1 2 |
| Using memory aid – composite group average | 44 86 69 70 6 12 4.61 1 0.032 45.19 1 <0.001 |
| Used memory notes at work | 33 65 59 60 2 12 |
| Used memory notes at home | 26 51 30 31 2 4 |
| Felt dependent on memory notes | 31 61 34 35 3 6 |
| Difficulties related to general/executive cognitive function – composite group average | 49 96 39 40 9 18 43.95 1 <0.001 7.18 1 0.007 |
| Felt mentally slow | 40 78 31 32 2 4 |
| Difficulties collecting your thoughts | 31 61 15 16 2 4 |
| Difficulties multitasking | 36 71 16 17 4 8 |
| Difficulties with problem solving | 33 65 15 16 4 8 |
| Difficulties with problem solving | 19 37 8 8 4 8 |

Note: SASCI-Q = Sahlgrenska Self-reported Cognitive Impairment Questionnaire, ED = exhaustion disorder (i.e. still fulfilling criteria for ED at the follow-up 7-12 after ED baseline diagnosis); EDrec = recovered exhaustion disorder (i.e. no longer fulfilling criteria for ED at the follow-up); HC = healthy controls; $\chi^2$ = chi square; Cut-offs for positive outcome: a once a week or more; b 2–3 occasions or more; c moderately or completely apply; d three times a week or more; e on about half of all occasions or more. The results presented in bold are the composite measures.
Fig. 2. Radar charts showing positive outcomes on SASCI-Q items for the cognitive composite score (2a), daily life activity (2b), and health and sleep factors (2c). Notes: The statistical analysis are presented in Tables 3, 4, and 5. ED = exhaustion disorder patients still clinically exhausted seven years after seeking care, EDrec = exhaustion disorder patients clinically recovered seven years after seeking care, HC = healthy controls.

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Table 3. Daily life activities items included in SASCI-Q during the last month for the three groups included in this study (ED, EDrec and HC) and group comparisons. A composite measure was calculated for themes containing two items, showing percentage of individuals classified as scoring a positive outcome for at least one item within respective theme.

| Themes and items from SASCI-Q                                      | ED       | EDrec    | HC       | ED vs EDrec, $\chi^2$ | EDrec vs HC, $\chi^2$ |
|-------------------------------------------------------------------|----------|----------|----------|------------------------|------------------------|
| Being physically active – composite group average                 | 43.84    | 82.84    | 47.94    | 0.010 1 0.920          | 3.155 1 0.076          |
| Walking at least three days a week for at least 15 minutes        | 35.69    | 71.73    | 42.84    |                        |                        |
| Engaging in a physically demanding activity at least once a week   | 26.51    | 66.68    | 32.64    |                        |                        |
| Engaging in leisure and cultural activities – composite group average | 36.71    | 89.91    | 46.92    | 10.157 1 0.001        | 0.058 1 0.810          |
| Engaging in any form of leisure activity outside the home at least once a week | 35.73    | 89.92    | 46.92    |                        |                        |
| Gone to the movies, theatre, musical concerts, sport events or similar kinds of events, at least once a week | 2.4      | 6.6      | 10.20    |                        |                        |
| Any reading 30 min per day - group average                        | 21.42    | 62.63    | 47.94    | 6.079 1 0.014         | 16.115 1 <0.001        |
| Spent at least 30 minutes per day on any form of reading          | 21.42    | 62.63    | 47.94    |                        |                        |
| Engaging in social activities – group average                     | 20.39    | 65.68    | 44.88    | 11.087 1 0.001        | 7.155 1 0.007          |
| Met with friends, acquaintances or relatives at least once a week | 20.39    | 65.68    | 44.88    |                        |                        |
| Difficulties with getting things done – group average             | 15.29    | 80.82    | 47.96    | 39.587 1 <0.001       | 5.672 1 0.017          |
| Carried through more than half of everything that you planned     | 15.29    | 80.82    | 47.96    |                        |                        |
| Watching TV – group average                                      | 28.55    | 71.73    | 32.74    | 5.051 1 0.025         | 0.011 1 0.917          |
| On average watched TV less than two hours per day                 | 28.55    | 71.73    | 32.74    |                        |                        |

Note: SASCI-Q = Sahlgrenska Self-reported Cognitive Impairment Questionnaire, ED = exhaustion disorder (i.e. still fulfilling criteria for ED at the follow-up 7–12 years after ED baseline diagnosis); EDrec = recovered exhaustion disorder (i.e. no longer fulfilling criteria for ED at the follow-up); HC = healthy controls; $\chi^2$ = chi square. The results presented in bold are the composite measures.

Table 4. Percentage of patients and controls replying positive for health and sleep items included in SASCI-Q and group comparisons.

| Item                                      | ED       | EDrec    | HC       | ED vs EDrec, $\chi^2$ | EDrec vs HC, $\chi^2$ |
|-------------------------------------------|----------|----------|----------|------------------------|------------------------|
| Been ill for at least one day             | 27.53    | 23.24    | 24.14    | 12.465 1 <0.001       | 0.363 1 0.547          |
| Been ill six days or more                 | 17.33    | 8.8      | 6.12     | 14.748 1 <0.001       | 0.569 1 0.451          |
| Experienced any strain or stress          | 51.100   | 87.91    | 60.30    | 5.093 1 0.024         | 19.371 1 <0.001        |
| Experienced daily strain or stress        | 22.43    | 15.16    | 6.3      | 13.385 1 <0.001       | 2.818 1 0.093          |
| Felt tired during the day, for half of the days or more             | 44.86    | 35.37    | 14.7     | 32.429 1 <0.001       | 8.092 1 0.004          |
| Slept 6 hours or less, on average per night | 16.31    | 38.39    | 36.19    | 0.878 1 0.349         | 0.141 1 0.707          |
| Slept 9 hours or more, on average per night | 9.18     | 6.4      | 8.4      | 4.821 1 0.028         | 0.171 1 0.679          |

Note: SASCI-Q = Sahlgrenska Self-reported Cognitive Impairment Questionnaire, ED = exhaustion disorder (i.e. still fulfilling criteria for ED at the follow-up 7-12 after ED baseline diagnosis; EDrec = recovered exhaustion disorder (i.e. no longer fulfilling criteria for ED at the follow-up); HC = healthy controls; $\chi^2$ = chi square.

Exhaustion disorder 7–12 years previously. The main finding was that patients who still fulfilled the criteria for ED reported widespread problems related to cognition, fatigue, and daily life functioning, leaving few areas unaffected. These results highlight the profound association between ED and the ability to lead a fulfilling life. We also found that although the recovered ED patients reported fewer problems than the patients who still fulfilled the ED criteria, they nonetheless reported more pronounced symptoms related to cognitive functioning and tiredness compared to controls, despite the long follow-up time. Thus, even in the group who no longer fulfilled the clinical criteria for exhaustion, many individuals seem to be struggling with remaining symptoms such as fatigue and cognitive problems.

Patients with ED initially report a considerable burden of symptoms, causing a challenge not only for the individual but also for the health care system, the social insurance system, and the workplace. Despite this, little is known about the long-term outcome of the condition. A few longitudinal studies have been previously published, showing that around one third of patients with exhaustion still report physical fatigue and exhaustion symptoms 2 to 3 years after seeking care (Glise et al., 2012, 2014, 2020; Hatinen et al., 2009; Stenlund et al., 2012). Similarly, several studies have shown that former patients with exhaustion/clinical burnout experience cognitive impairment for up to 3 years (Jonsdottir et al., 2017; Oosterholt, Van der Linden, Maes, Verbraak & Kompier, 2012; Österberg, Karlson, Malmberg & Hansen, 2012). The present study adds to the evidence that perceived fatigue and cognitive problems among patients with stress-related exhaustion seem to be even more long-lasting and apparently not easily restored. Differences between the three groups were seen in almost all aspects related to everyday cognitive functioning and fatigue, which separated the three groups clearly. Patients still fulfilling the criteria are also clearly separate from the clinically recovered group on the questions.
signalling an outgoing, inquisitive lifestyle such as engaging in social activities and getting things done.

When studying the clinically recovered group, we found significant improvement regarding cognitive symptoms compared to those who still fulfilled the ED criteria, but this group still differed from healthy controls regarding symptoms related to cognitive functioning and fatigue. The group as whole differ somewhat regarding daily activities but patients and controls of similar age do not differ regarding daily activities. Thus, it seems that the clinically recovered ED group reported intermediary symptoms, particularly regarding cognitive function, when compared to the ED and control group, indicating that despite no longer fulfilling the criteria for ED, the recovered group still experience considerable negative long-term effects. This group has also been shown to report several other remaining problems such as reduced stress tolerance (Glise et al., 2020). The question remains of whether these former patients are generally still recovering, meaning that all patients will eventually move towards full or almost full recovery, or if there are two different groups: one that is slowly recovering and another that does not seem to show any recovery over time. In any case, most patients with previous ED seem to be affected by their condition for a considerable period of time, and the detrimental effects of the condition upon cognition and general well-being have previously not been fully acknowledged. It is still unknown whether different kinds of treatment can affect these remaining symptoms or if other factors, such as co-morbid conditions or the continued presence of prolonged stress exposure, can explain this lack of recovery.

One possibility that should also be raised is that some aspects measured in this study, such as less daily reading and less social contact, could have been present before the onset of ED. However, we consider this to be unlikely, since ED patients are generally highly educated and when the recovered group is compared to the healthy control group of similar age, no significant differences were seen between the groups, indicating that a lower participation rate in different social activities is most probably not a premorbid feature among the patients.

Since ED is a symptom-based diagnosis, a thorough evaluation of associated symptoms is clearly warranted. A better phenomenological understanding of ED would not only increase our understanding of the condition but could also improve the diagnostic criteria. While several items in the SASCI-Q overlap with commonly used checklists for ED, the SASCI-Q is more comprehensive and encompasses many aspects of cognitive functioning and related well-being. It has been validated in several other studies as well as in patients with subjective cognitive impairment seeking care at a memory clinic, and proved effective both in discriminating these patients from healthy controls and in identifying symptoms linked to cognitive deterioration (Eckerstrom et al., 2013). One possible drawback of using a comprehensive questionnaire is that this is burdensome for the patient, especially if it is only one of several questionnaires administered prior to or during a visit. Strategies to ameliorate this might include staggered testing and transfer of information between questionnaires with interchangeable items. Based on our findings in the present study, we argue that the SASCI-Q or similar comprehensive questionnaires could be a valuable complement to the evaluation of ED patients.

There are several limitations of the present study that should be addressed. We could not analyze self-reported cognitive impairment over time, since this was not assessed when the patients initially sought care. Additionally, the controls were older than the patients and had fewer years of education. While this is unfortunate, age and fewer years of education are negatively correlated to general cognitive functioning (Harada, Natelson Love & Triebel, 2013; Opdebeeck, Martyr & Clare, 2016). To control for the age difference between the clinically recovered patient group and healthy controls, sub analysis was performed including similar age groups. These analyses did not considerably affect the outcome regarding cognitive functions and fatigue but did affect themes related to daily activities. Thus, older patients, probably not working or working less due to pension, reported similar rate of daily activities as healthy controls in the same age group. Although these differences were significant, all groups reported a mean education over 12 years, indicating that the individuals included in this study reported education exceeding high-school level. We also checked if the lower educational level among the healthy controls mattered regarding the outcome of cognitive function. Comparing patients that had recovered with the healthy controls, stratifying the group that report higher educational level (≥13 years) did not change the results. Very few men participated in this study, and thus no statistical analysis could be performed comparing women and men. Previous studies have shown that female and male patients with ED do not seem to differ considerably regarding burden of symptoms and/or duration of recovery (Glise et al., 2012, 2014; Jonsdottir et al., 2013), and the pattern seen in the present study was also similar for men and women.

Our results have several clinical implications. Most of these patients were highly educated, and it seems likely that the long-lasting impact on cognition and everyday functioning seen in this study affects both work performance and life situation. Preventive measures are urgent, as the consequences for the individual seem to be extended. We have previously raised concerns whether some of these residual symptoms are permanent, at least in the group still fulfilling the criteria for ED such a long time after first seeking care, and the present results show that these concerns are still relevant. This is particularly a concern for the symptoms related to cognitive functioning, which raises the urgency of explaining the reason for this long-lasting influence on brain function in these individuals.

CONCLUDING REMARKS
Patient who still fulfill the diagnostic criteria for ED 7–12 years after initial diagnosis report widespread problems related to the aspects of cognition and fatigue and daily life functioning that were investigated in the current study. Their counterparts who no longer fulfill the criteria at follow-up still report more problems related mainly to cognitive functioning and fatigue compared to controls, suggesting considerable negative long-term effects of the condition despite clinical improvement.

COMPETING INTERESTS
The authors declare that they have no competing interests.
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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

REFERENCES

Eckerstrom, M., Skoogh, J., Rolstad, S., Gothlin, M., Steineck, G., Johansson, B. & Wallin, A. (2013). Sahlgrenska Academy Self-reported Cognitive Impairment Questionnaire (SASCI-Q) – a research tool discriminating between subjectively cognitively impaired patients and healthy controls. *International Psychogeriatrics*, 25, 420–430.

Eskildsen, A., Fentz, H. N., Andersen, L. P., Pedersen, A. D., Kristensen, S. B. & Andersen, J. H. (2017). Perceived stress, disturbed sleep, and cognitive impairments in patients with work-related stress complaints: a longitudinal study. *Stress*, 20, 371–378.

Forsäkringskassan. (2020). Sjukfrifinansiering efter psykiatriska diagnoser. Social insurance report 2020:8. The Swedish Social Insurance Agency, Stockholm.

Glise, K., Ahlborg, G. Jr & Jonsdottir, I. H. (2012). Course of mental symptoms in patients with stress-related exhaustion: does sex or age make a difference? *BMC Psychiatry*, 12, 18.

Glise, K., Ahlborg, G. Jr & Jonsdottir, I. H. (2014). Prevalence and course of somatic symptoms in patients with stress-related exhaustion: does sex or age matter. *BMC Psychiatry*, 14, 118.

Glise, K., Wiegner, L. & Jonsdottir, I. H. (2020). Long-term follow-up of residual symptoms in patients treated for stress-related exhaustion. *BMC Psychology*, 8, 26.

Grossi, G., Perski, A., Osika, W. & Savic, I. (2015). Stress-related exhaustion disorder–clinical manifestation of burnout? A review of assessment methods, sleep impairments, cognitive disturbances, and neuro-biological and physiological changes in clinical burnout. *Scandinavian Journal of Psychology*, 56, 626–636.

Harada, C. N., Natelson Love, M. C. & Triebel, K. L. (2013). Normal cognitive aging. *Clinics in Geriatric Medicine*, 29, 737–752.

Hatien, M., Kinnunen, U., Makikangas, A., Kalimo, R., Tolvanen, A. & Pekkonen, M. (2009). Burnout during a long-term rehabilitation: Comparing low burnout, high burnout – benefited, and high burnout – not benefited trajectories. *Anxiety Stress and Coping*, 22, 341–360.

Jonsdottir, I. H., Hagg, D. A., Glise, K. & Ekman, R. (2009). Monocyte chemotactic protein-1 (MCP-1) and growth factors called into question as markers of prolonged psychosocial stress. *PLoS One*, 4, e7659.

Jonsdottir, I. H., Nordlund, A., Ellbin, S., Ljung, T., Glise, K., Wahlborg, P. & Wallin, A. (2013). Cognitive impairment in patients with stress-related exhaustion. *Stress*, 16, 181–190.

Jonsdottir, I. H., Nordlund, A., Ellbin, S., Ljung, T., Glise, K., Wahlborg, P. et al. (2017). Working memory and attention are still impaired after three years in patients with stress-related exhaustion. *Scandinavian Journal of Psychology*, 58, 504–509.

Ohman, L., Nordin, S., Bergdahl, J., Slunga Birgander, L. & Stigsdotter Neely, A. (2007). Cognitive function in outpatients with perceived chronic stress. *Scandinavian Journal of Work, Environment & Health*, 33, 223–232.

Oosterholt, B. G., Maes, J. H. R., Van der Linden, D., Verbraak, M. & Kompier, M. A. J. (2016). Getting better, but not well: A 1.5 year follow-up of cognitive performance and cortisol levels in clinical and non-Clinical burnout. *Biological Psychology*, 117, 89–99.

Oosterholt, B. G., Van der Linden, D., Maes, J. H. R., Verbraak, M. J. K. & Kompier, M. A. (2012). Burnout and cognitive functioning of burnout patients before and after a period with psychological treatment. *Scandinavian Journal of Work, Environment & Health*, 38, 358–369.

Opdebeeck, C., Martyr, A. & Clare, L. (2016). Cognitive reserve and cognitive function in healthy older people: A meta-analysis. *Neuropsychology, Development, and Cognition. Section B, Aging*, 23, 40–60.

Osterberg, K., Karlson, B. & Hansen, A. M. (2009). Cognitive performance in patients with burnout, in relation to diurnal salivary cortisol. *Stress*, 12, 70–81.

Osterberg, K., Karlson, B., Malmberg, B. & Hansen, A. M. (2012). A follow-up of cognitive performance and diurnal salivary cortisol changes in former burnout patients. *Stress*, 15, 589–600.

Sandstrom, A., Rhedin, I. N., Lundberg, M., Olsson, T. & Nyberg, L. (2005). Impaired cognitive performance in patients with chronic burnout syndrome. *Biological Psychology*, 69, 271–279.

Stenlund, T., Nordin, M. & Jarvholm, L. S. (2012). Effects of rehabilitation programmes for patients on long-term sick leave for burnout: a 3-year follow-up of the REST study. *Journal of Rehabilitation Medicine*, 44, 684–690.

Wallin, A., Nordlund, A., Jonsson, M., Lind, K., Edman, Å., Götlin, M. et al. (2016). The Gothenburg MCI study: Design and distribution of Alzheimer’s disease and subcortical vascular disease diagnoses from baseline to 6-year follow-up. *Journal of Cerebral Blood Flow and Metabolism*, 36, 114–131.

World Health Organization. (1992). *International classification of diseases and related health problems, tenth revision (ICD-10)*. Geneva: World Health Organization (WHO).

Zigmund, A. S. & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361–370.

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