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Cluster Headache (CH) and work life in the European Union: a survey from the European Migraine and Headache Alliance

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Abstract. This survey is about the impact on work life of Cluster Headache (CH) patients living in the European Union. The survey used in this study was developed by EMHA in collaboration with its members and was based on information from literature and existing questionnaires and explored the impact of CH on the work life in terms of employment status, absenteeism, presenteeism, work life expectancy, interference on education and career, work bullysm and interference on the salary. The study was carried out online through SurveyMonkey on February 2019 and had a very large participation (1500 patients completed the survey, 61% with episodic CH, 51% were males). Overall, 29% of the chronic CH patients reported a premature exit from the work-force (14% of the full sample, 5.5% of the episodic CH patients). Of these, 6% were early retired (2.7% of fhe full sample); 22.5% reported to be unfit for paid work because of CH (11.3% of the full sample, 35 % of these recognized as permanently disabled); 13.7 % is receiving finantial compensation for CH (6.8% of the full sample);12.7% has lost 1 job (7.5% of the full sample), and 8% has lost more than 1 job (6% of the full sample). On average CH patients reported to have missed 14 work days in the past 3 months (the number of missed days was significantly higher in the CCH ,19.8±12 days , than in the ECH, 4±5 days) and 75% of the patients reported an interference on their career (90% of the CCH subgroup). This survey has revealed that the burden of CH through unemployment, absenteeism, presenteeism, early retirement and reduced worklife expectancy is dramatic and damaging both patient's quality of life and economy.

Key words: cluster headache, worklife, survey results

INDAGINE SULL'IMPATTO DELLA CEFALEA A GRAPPOLO SULLA VITA LAVORATIVA DEI PAZIENTI IN EUROPA: RIASSUNTO DEI RISULTATI PRINCIPALI

Riassunto. Questo studio ha avuto l'obiettivo di valutare l'impatto che la cefalea a grappolo (CH: cluster headache) ha sulla vita lavorativa di pazienti residenti nei paesi della UE. Il questionario utilizzato è stato preparato ad hoc dalla EMHA, sulla base di quelli esistenti in letteratura ed ha esplorato la disabilità occupazionale valutando il tasso di occupazione, l'assenteismo, il presenteismo, l'aspettativa di vita lavorativa, fenomeni di bullismo lavorativo e l'interferenza della malattia su carriera, formazione e stipendio. Lo studio è stato effettuato online nel mese di febbraio 2019 ed ha visto la partecipazione di 1500 pazienti (40% con forma cronica, 51% di maschi). Nell'insieme il 29% dei pazienti affetti da CH cronica sono usciti prematuramente dal mondo del lavoro (14% di tutti i pazienti, 5.5% di quelli affetti dalla forma episodica). Il 6% ha riportato di essersi pensionato prematuramente (2.7% dell'intero campione), il 22.5% ha riportato di non essere in grado di lavorare per colpa della CH (11% dell'intero campione; il 35% di questi ha una forma di riconoscimento di disabilità permanente); il 13.7% sta ricevendo una forma di compensazione economica (6.8% dell'intero campione); il 12.7% dichiara di avere perso un lavoro e l'8% dei pazienti con forma cronica dichiara di aver perso più di un lavoro. In media i pazienti affetti da cefalea a grappolo riferiscono di aver perso 14 giorni di lavoro negli ultimi 3 mesi (sono 19 in quelli affetti da forma cronica e 4 in quelli affetti da una forma episodica). Il 75% dei pazienti riferisce interferenza della CH sulla carriera (90% degli affetti da una forma episodica). L'indagine ha mostrato che l'impatto della cefalea a grappolo sulla vita lavorativa dei pazienti è drammatico e coinvolge sia la qualità della vita del paziente che l'economia.

Parole chiave: cefalea a grappolo, vita lavorativa, risultati di indagine

Investigación sobre el impacto de la dolor de cabeza en racimo sobre la vida laboral de los pacientes en Europa: resumen de los principales resultados

Resumen. Esta encuesta trata sobre el impacto en la vida laboral de los pacientes con dolor de cabeza en racimo (CH: cluster headache) que viven en la Unión Europea. La encuesta utilizada en este estudio fue desarrollada por EMHA en colaboración con sus miembros y se basó en la información de la literatura y los cuestionarios existentes y exploró el impacto de CH en la vida laboral en términos de situación laboral, ausentismo, presentismo, esperanza de vida laboral, interferencia En educación y carrera, bullysm trabajo e interferencia en el salario. El estudio se realizó en línea a través de SurveyMonkey en febrero de 2019 y tuvo una participación muy grande (1500 pacientes completaron la encuesta, 61% con CH episódica, 51% eran hombres). En general, el 29% de los pacientes con CH crónico informaron una salida prematura de la fuerza laboral (el 14% de la muestra completa, el 5,5% de los pacientes con CH episódicos). De estos, el 6% se jubiló anticipadamente (2,7% de la muestra completa); El 22.5% informó que no era apto para el trabajo remunerado debido a CH (11.3% de la muestra completa, 35% de los cuales se reconoció como discapacitados permanentes); 13.7% está recibiendo compensación financiera por CH (6.8% de la muestra completa), 12.7% ha perdido 1 trabajo (7.5% de la muestra completa) y 8% ha perdido más de 1 trabajo (6% de la muestra completa). En promedio, se informó que los pacientes con CH perdieron 14 días laborales en los últimos 3 meses (el número de días perdidos fue significativamente mayor en el CCH, 19.8±12 días, que en el ECH, 4±5 días) y el 75% de los pacientes reportaron una interferencia en su carrera (90% del subgrupo CCH). Esta encuesta ha revelado que la carga de CH a través del desempleo, el ausentismo, el presentismo, la jubilación anticipada y la reducción de la esperanza de trabajo es dramática y perjudica la calidad de vida y la economía de ambos pacientes.

Palabras clave: dolor de cabeza en racimo; vida laboral; resultados de la encuesta

Introduction

This survey is about the impact on work life of Cluster Headache (CH) patients living in the European Union.

Cluster headache (CH) is a quasi-rare (prevalence 1:1000) excruciating form of primary headache, characterized by recurrent unilateral, short attacks of very severe headache, accompanied by autonomic symptoms/signs (i.e. rhinorrhea/nasal congestion, lacrimation, conjunctival injection) and restlessness. These attacks most commonly appear in clusters i.e. active periods separated by pain-free remission periods (1) but 20% of the patients suffer for a chronic unremitting form.

CH is considered the most severe pain condition that afflicts humans (2). Patients usually describe the pain as "having a red hot poker forced through my eye", an "agony", "a trip to hell you can't control" and they report that the intensity is so extreme it is unlike anything they have ever experienced. The severity of pain has earned it the nickname "suicide headache" and a suicidal risk exists in this condition (in a recent survey 55% of CH patients reported suicidal thoughts, 3)

Due to the extraordinary severity of pain the personal burden related to CH comprising psychiatric complaints, drug dependence, poor quality of life, socio-relational and familial restrictions is high as it seems to be the societal burden due to increased healthcare utilization and negative impact on work(4,5,6). A

German study conducted on a small clinical population of CH patients showed that average direct and indirect costs of cluster headache in 2010 were €5,963 per person during a six months period (5).In the United States the Cluster Headache Survey conducted in 2008 reported that almost 20% of the patients had lost a job due to cluster headache, while another 8% were out of work or on disability (3). Another recent paper from US estimated that patients with cluster headache have higher indirect costs associated with absenteeism (4928 $ per-patient-per year) than migraineurs (943$ PPPY) (7).

Further evidence that CH may have an impact on CH employment comes from South-Korea where it has been reported in a small clinical population of CH patients that the proportion of employees was lower in the CH group compared with other headache controls (67.6% vs 84.2%) (8).

Overall, evidences of the impact of the CH on employment status and job burden are sparse and anecdotal and large European survey of the full impact of CH on the multiple aspects of work life is lacking.

The European Migraine and Headache Alliance Cluster Headache Special Interest Group (EHA CHSIG) involved its member organizations into a survey to find out more about the experience of occupational disability from the CH patients' view across the EU.

On February 2019 a large-scale online survey was launched. The objective was to gather updated information about the impact that Cluster Headaches has on the work life of the CH sufferers and to inform policy-making and ensure that future the advocacy actions are developed with consideration of the special need of CH patients

Methodology

The survey used in this study was developed by EMHA in collaboration with its members: national CH patients organizations and scientific advisors. It was based on information from literature and existing questionnaire such as Pain Alliance Europe Survey on chronic pain, Eurolight questionnaire, SF-HLQ, WHO-HPQ). In total the survey consisted in 30 question exploring demographics, informations about CH, and the impact of CH on the work life in terms of employment status, absenteeism, presenteeism, work life expectancy, interference on education and career, work bullysm and interference on the salary.

EMHA- CH SIG proposed it in ten languages: English, German, French, Spanish, Italian, Flemish, Polish, Swedish, Finnish, and Danish.

The study was carried out online through SurveyMonkey on February 2019. All the member organizations were asked to promote the survey on their websites and reminders to complete the survey were sent by CH SIG member organisations through targeted email, internal and external newsletters and social media reminders

Results

Demographics and information about CH diagnosis and severity

In total 1500 respondents filled in the online survey. Figure 1 show the percentage number of respondents per country.

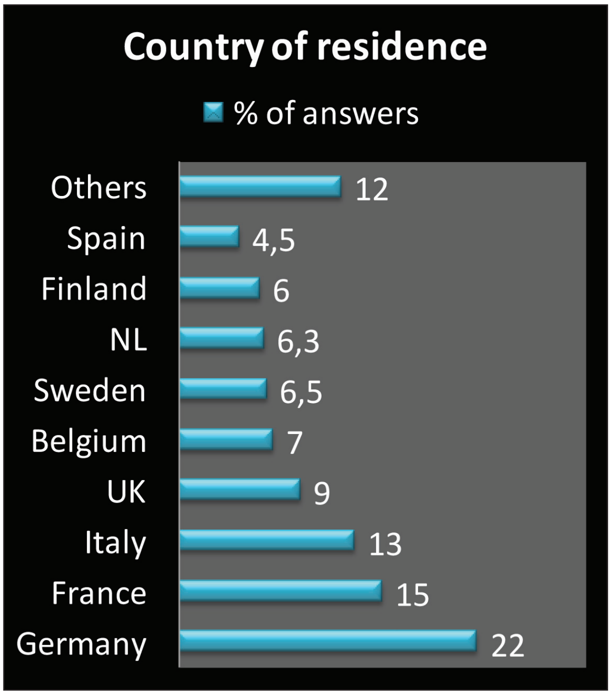

Figura 1. Percentage of respondents per country

Overall 50.8% of the participants were male (the male to female ratio 1.02 is far lower than that reported in epidemiological studies on CH and is conditioned by having completed the recruitment through patients'associations members with an overrepresentation of chronic forms). 41.0% of the patients suffered for chronic CH (figure 2).

Only 3% of the respondents were over 65 years which is generally considered the retirement age.

We asked to the respondents about their net household income per year. 20% of the surveyed sample (24% of the CCH patients) declared an household income per year lower than 18.000 euro that is beyond the monetary value at risk for poverty for most of the participating countries.

The mean duration of CH was 11.4±10 years and the mean time reported to get a diagnosis after the first visit to a health professional was 6±7.4 years (9).

We asked to the respondents how many severe attacks they had in the last twelve months. The responses were split fairly among the different frequency classes (figure 3) with a sisgnificantly higher proportion of CCH patients experiencing more tha 250 severe attacks per year ($p<0.05$)

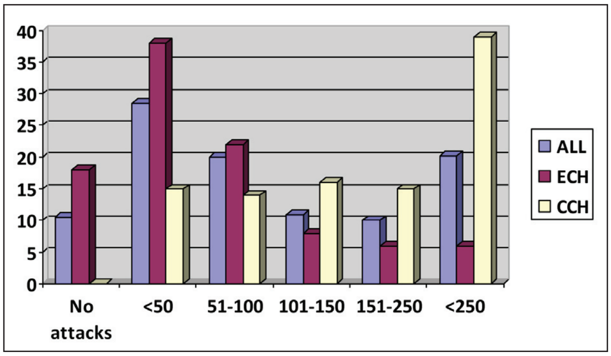

Figura 3. Number of severe attacks experienced in the last year

CH and work life? What is the situation?

Employment status

We asked to the patients if they have currently a paid job? and to specify better they current situation in a list of options that was different for the unemployed and the employed ones.

The employment rate and the causes for unemployment have been summarized in figure 4 and 5.

The unemployment rate was significantly higher in the CCH vs ECH (40% vs. 17%).

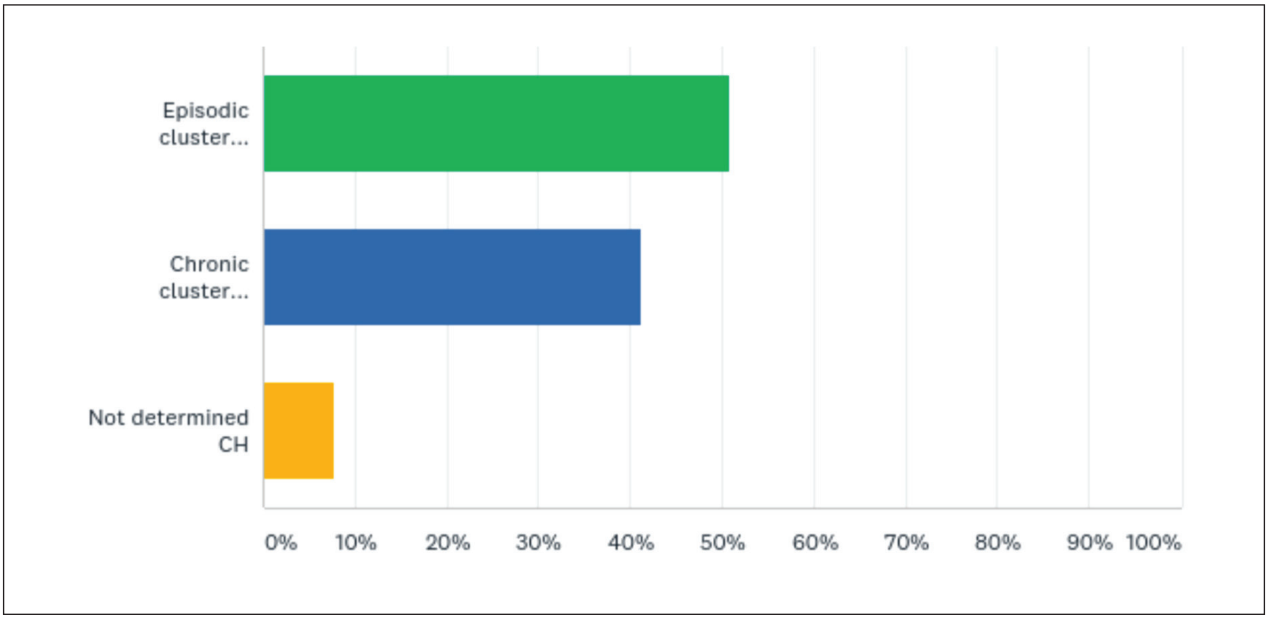

Figura 2. Percentage of CH subgroup diagnosis

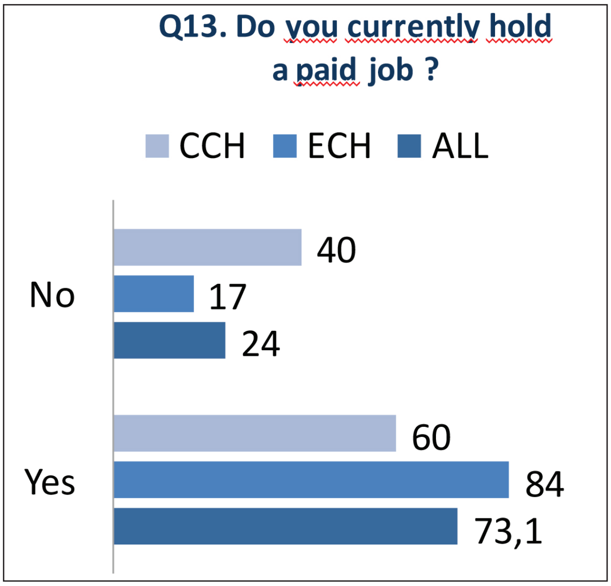

Figura 4. Employment and unemployment rate in the full sample , ECH and CCH

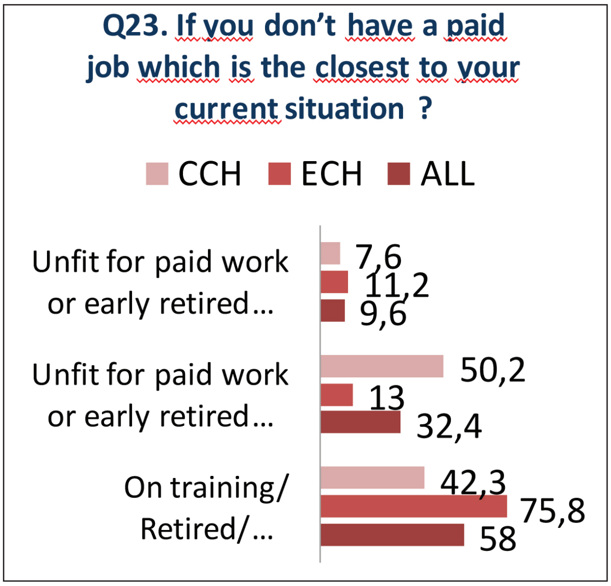

Figura 5. Reported causes for not having a paid job

Figure 5 report the cause for unemployment. A significantly higher proportion of CCH patients reported to be unemployment (unfit for paid work or early retired) because of CH (32.4% of the full sample).

Overall, 29% of the chronic CH patients report a premature exit from the work-force (14% of the full sample, 5.5% of the episodic CH patients). Of these, 6% were early retired (2.7% of fhe full sample); 22.5% reported to be unfit for paid work because of CH (11.3% of the full sample,35 % of these recognized as permanently disabled); 13.7 % is receiving finantial compensation for CH (6.8% of the full sample); 12.7% has lost 1 job (7.5% of the full sample), and 8% has lost more than 1 job (6% of the full sample).

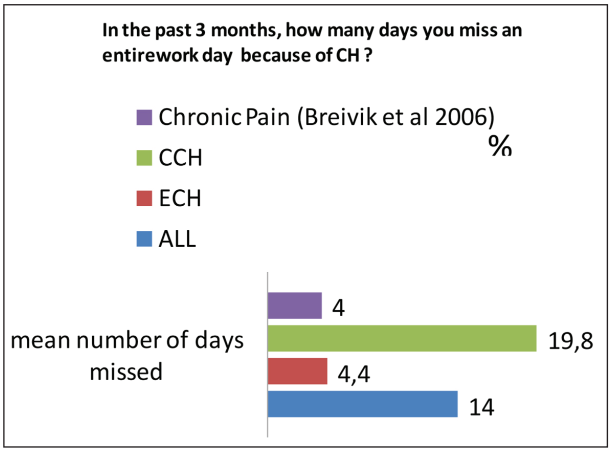

Figura 6. Mean number of work days missed in the last 3 months

Absenteeism

We asked to report how many days in the last 3 months they have missed an entire work day because of CH. As reported in figure 7 on average CH patients reported toh ave missed 14 work days (the number of missed days was significantly higher in the CCH, 19.8±12 days , than in the ECH, 4±5 days; in the episodic subgroup 43% of the patients reported to be in remission phase of the disease). The number of missed days is significantly higher than dose abstracted by the study of Breivik on chonic pain patients.

Coherently a significant higher proportion of CCH patients rpoerted to be in a long term sick leave (>30 days); it was 11% of the CCH group vs 2.4% of the ECH group, 5.4% of the full sample).

Presenteeism

We asked to report how many days in the last 3 months the CH patients could do less than half of usual amount of job because of their CH. As reported in figure 7, on average CH patients reported to have

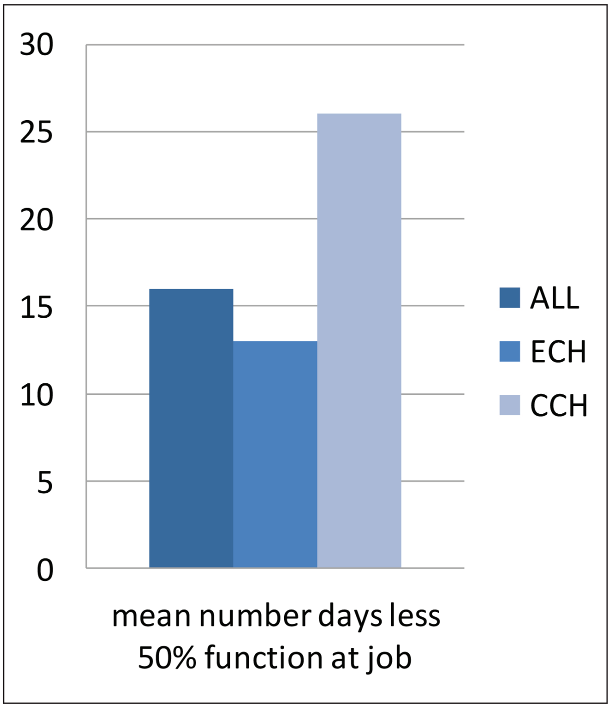

Figura 7. Mean number of days patients could do less than half of usual amount of their job because of CH

been at work with a 50% decreased ability for 26 work days (the mean number of 50%reduced work ability was significantly higher in the CCH, 26±12 days, than in the ECH, 13±10 days).

We asked to CH patients who went to work to rate their level of agreement to a series of statements about the interference of the disease on theirjob ability in the last 3 months. 76% of the CH reported ta have had concentrations problems and sleepiness often/nearly always (it was 84% of the CCH), 67.5% reported toh ave worked at a slower pace (it was 72% of the CCH); finally almost 50% reported difficulty in taking decision and the necessity to postpone work.

Work life expectancy, workplace bullysm, interference of CH on career, education and salary

When asked if they fear to lose their job 60% of the CCH patients and 45% of the ECH patients answered yes.

When asked to rate from 0 to 100 (where 0 is it will never happen to me and 100 is it will happen for sure) the level of agreement with the sentence "I can keep working in this job for more than 5 years", 16% of the CCh and 4.5% of the ECH rated 0, that is the higher level of skepticism.

10% of the sample reported to have been victim of bullying (request to change job, demotion, refusal of adopting any form of job adaptation at your personal request, etc) at their workplace (it was 14% of the CCH and 6.8% of the ECH).

Overall 32% of the CH patients reported that their headache have interfered with their education, and 75% reported an interference on their career (90% of the CCH subgroup).

When asked "how much your income has dropped due to the impact of your CH on your job situation", a significant higher proportion of ECH vs CCH reported that the income has not dropped (43% vs 22%, $p<0.05$) , whereas a significantly higher proportion of CCH vs ECH reported that they were receiving less than 50% of the salary (35% vs 15%, $p<0.01$)

Conclusions and policy implications

- The burden of CH through unemployment, absenteeism, presenteeism, early retirement and reduced worklife expectancy is dramatic and damaging both patient's quality of life and economy
- CCH have an occupational disability greater than the one experienced by patients affected by chronic pain or chronic disORDERS
- The impact of CH on worklife must be a component in the rationale for improving CH management and research
- The european and national institutions should promote policies addressing the impact of CH on employment
- The european and national institutions should promote The interconnection between services dealing with health, employment, research and social protection policies to allow a greater efficiency in CH management
- The european and national institutions should recognise that patients are part of the solution and ensuring patients' perspective on occupational disability is collected and used #CHPAINFREEFUTURE

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