Received: 25 July 2023 | Accepted: 9 October 2023

DOI: 10.1111/head.14646

RESEARCH LETTER

A qualitative study on the long-term effectiveness of occipital nerve stimulation in patients with chronic cluster headache

E. Kurt MD[1,2] | R. W. Volkers BSc[1] | Y. Engels PhD[1] | W. M. Mulleners MD, PhD[3] | R. L. Witkam MD[1] | R. T. M. van Dongen MD, PhD[1]

[1]Department of Anesthesiology, Pain and Palliative Care, Radboud University Medical Centre, Nijmegen, The Netherlands

[2]Department of Neurosurgery, Radboud University Medical Centre, Nijmegen, The Netherlands

[3]Department of Neurology, Canisius-Wilhelmina Hospital, Nijmegen, The Netherlands

Correspondence
E. Kurt, Department of Neurosurgery, Radboud University Medical Centre, Geert Grooteplein Zuid 10, 6525 EZ, Nijmegen, The Netherlands.
Email: erkan.kurt@radboudumc.nl

Keywords: cluster headache, neuromodulation, occipital nerve stimulation, quality of life

INTRODUCTION

Cluster headache (CH) is a headache disorder that greatly incapacitates patients and leads to a considerable negative impact on their well-being, the ability to perform daily activities or work, social functioning, and quality of life (QoL).[1,2] About 15% of patients with CH have no proper response to medication, in which case it is labeled as "medically intractable chronic cluster headache" (MICCH).[3] For these patients, occipital nerve stimulation (ONS) could provide a last resort[3,4] and can be very effective as it significantly reduces headache frequency and intensity[5]; however, there are no qualitative studies yet that have studied the long-term effects of ONS on QoL. Therefore, this study aimed to provide a qualitative in-depth insight into the long-term effect of ONS in patients with MICCH using a broad view on QoL.

METHODS

Included participants were part of the occipital nerve stimulation in medically intractable chronic cluster headache (study) or ONS in MICCH (study) (ICON) group[3] from the region of Nijmegen, The Netherlands. This ICON study was a double-blind randomized controlled clinical trial to assess the effectiveness of ONS in MICCH; in total 131 patients underwent ONS. From this group, 18 patients underwent the surgical procedure in our hospital, of whom 4 patients refused to participate in the current study stating that participation in the ICON study was enough for them. Qualitative semi-structured in-depth interviews were conducted with the remaining 14 patients to provide insight into the long-term effect of ONS using a broad view on QoL. The topic list was structured using the model of Positive Health[6] containing six domains: (1) bodily functions; (2) mental functions and perception; (3) spiritual/existential dimension; (4) QoL; (5) social and societal participation; and (6) daily functioning. The consolidated criteria for reporting qualitative research (COREQ) checklist was used to structure this study. Participants were encouraged to express their experiences and thoughts by using open-ended questions. Quantitative data (e.g., pain scores and attack duration) were collected as well from the retrieved data in medical records. The interviews were audio-recorded and transcribed verbatim. The coding of all interviews was done using Atlas.ti software. When all interviews were coded, the categories and themes were extracted for analysis. Participants were not subject to any additional treatment, nor were they required to behave in a particular way. Ethical approval was granted by the local research ethical committee of the region Arnhem-Nijmegen (dossier number: 2021-13326). The interviewer did not have any personal or professional relationship with the participants. Written informed consent was obtained from all participants.

Abbreviations: CH, cluster headache; ICON, occipital nerve stimulation in medically intractable chronic cluster headache (study) or ONS in MICCH (study); MICCH, medically intractable chronic cluster headache; ONS, occipital nerve stimulation; QoL, quality of life.

TABLE 1 Overview of participant characteristics.

Participant number	Sex	Age	Age at first cluster attack (years)	Duration of cluster disease at time of ONS placement (years)	ONS in situ (years)	Attack frequency before ONS	Attack frequency after ONS	Maximum pain score before ONS (NRS)	Maximum pain score after ONS (NRS)
1	Male	36	23	13	5	8/day	4/week	9–10	6
2	Female	46	37	9	5	5–6/day	2–3/day	7–10	3–6
3	Male	44	37	7	5	3–4/day	8–10/month	8	4–5
4	Female	65	63	2	6	6–10/day	3 in last 8 months	10	10
5	Female	64	55	9	8	8–10/day	2–3/week	9	7
6	Female	46	38	8	4	5–6/day	1/month	8–9	3–4
7	Male	72	69	3	5	3–4/week	3–4/week	9–10	3
8	Female	74	62	12	10	12/day	None in last 9 months	9–10	9–10
9	Female	31	29	2	8	10/day	5–6/day	10	8–10
10	Male	40	34	6	9	6/day	6/day	7–10	5
11	Male	63	60	3	8	6–7/day	4–5/night	8–10	2–3
12	Male	35	26	9	8	8–12/day	6–8/day	10	10
13	Female	35	33	2	4	4–12/day	1–3/day	8–10	6–8
14	Male	55	49	6	11	8/day	5–6 in last 9 months	10	1

Abbreviations: NRS, numeric rating scale; ONS, occipital nerve stimulation.

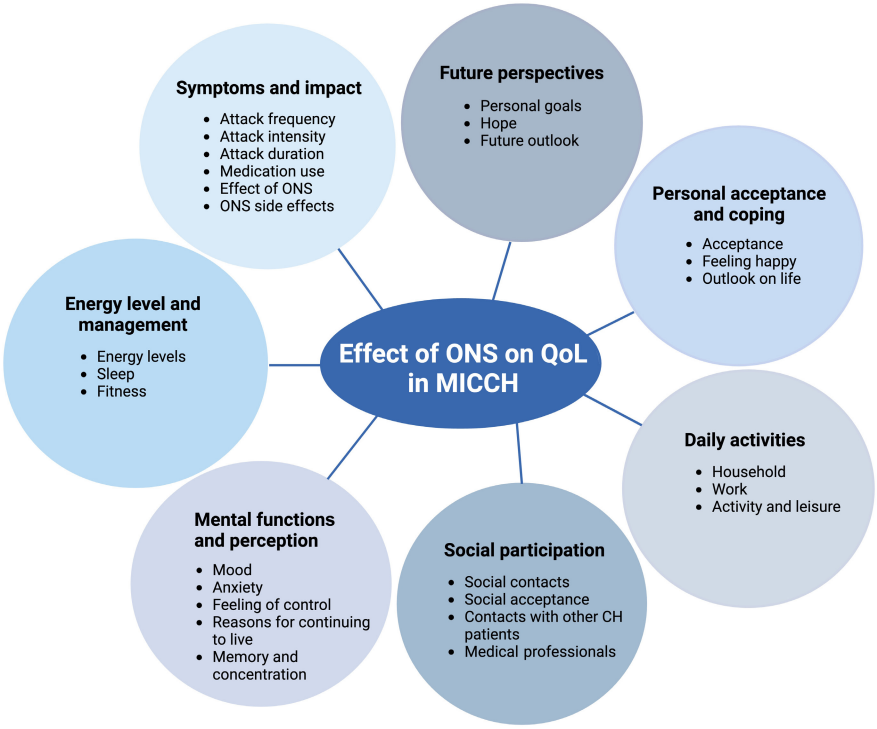

FIGURE 1 Overview of emerged categories and extracted themes. CH, cluster headache; MICCH, medically intractable chronic cluster headache; ONS, occipital nerve stimulation; QoL, quality of life. [Color figure can be viewed at wileyonlinelibrary.com]

RESULTS

A total of 14 participants were included (Table 1). Saturation was reached after 11 interviews as the remaining interviews yielded no novel themes. The participants comprised seven males and seven females, and median age was 46 years (ranging from 31 to 74 years). The median duration of CH prior to ONS implantation was 7 years (ranging from 2 to 13 years). The median follow-up time until the interview was 7 years (ranging from 4 to 10 years). The interviews lasted, on average, 63 min. Detailed participant characteristics can be found in Table 1. From the data, 27 categories emerged. From those, the researchers identified seven themes as depicted in Figure 1: (1) symptoms and impact; (2) energy level and management; (3) mental functions and perception; (4) social participation; (5) daily activities; (6) personal acceptance and coping; and (7) future perspectives.

COMMENTS

Although one of the limitations of this study arises from a potential selection bias, this semi-structured in-depth interview study shows long-term positive overall benefits of ONS on multiple domains of QoL in patients with MICCH. Generally, participants had increased mood and energy levels, a greater sense of feeling in control, more social participation and activities, a more positive future outlook, and better overall acceptance. These findings allow for more elaborate insight into the long-term effects of ONS and provide information for patients and practitioners on the expected outcomes of this treatment beyond reduction of attack frequency and pain intensity. This novel insight could help the implementation and the acceptance of this treatment as standard care in severe MICCH.

AUTHOR CONTRIBUTIONS

Study concept and design: E. Kurt, R. W. Volkers, R. L. Witkam. *Acquisition of data*: E. Kurt, R. W. Volkers. *Analysis and interpretation of data*: E. Kurt, R. W. Volkers, R. L. Witkam. *Drafting of the manuscript*: E. Kurt, R. W. Volkers, R. L. Witkam, R. T. M. van Dongen. *Revising it for intellectual content*: Y. Engels, W. M. Mulleners, R. T. M. van Dongen. *Final approval of the completed manuscript*: E. Kurt, R. W. Volkers, Y. Engels, W. M. Mulleners, R. L. Witkam, and R. T. M. van Dongen.

CONFLICT OF INTEREST STATEMENT

E. Kurt, R. W. Volkers, Y. Engels, W. M. Mulleners, R. L. Witkam, and **R. T. M. van Dongen** declare that they have had no conflict of interest in the conduct of this research.

REFERENCES

1. D'Amico D, Raggi A, Grazzi L, Lambru G. Disability, quality of life, and socioeconomic burden of cluster headache: a critical review of current evidence and future perspectives. *Headache*. 2020;60(4):809-818.
2. Torkamani M, Ernst L, Cheung LS, Lambru G, Matharu M, Jahanshahi M. The neuropsychology of cluster headache: cognition, mood, disability, and quality of life of patients with chronic and episodic cluster headache. *Headache*. 2015;55(2):287-300.

3. Wilbrink LA, De Coo IF, Doesborg PGG, et al. Safety and efficacy of occipital nerve stimulation for attack prevention in medically intractable chronic cluster headache (ICON): a randomised, double-blind, multicentre, phase 3, electrical dose-controlled trial. *Lancet Neurol*. 2021;20(7):515-525.
4. Wei DY, Goadsby PJ. Cluster headache pathophysiology—insights from current and emerging treatments. *Nat Rev Neurol*. 2021;17(5):308-324.
5. Aibar-Durán JÁ, Álvarez Holzapfel MJ, Rodríguez Rodríguez R, Belvis Nieto R, Roig Arnall C, Molet TJ. Occipital nerve stimulation and deep brain stimulation for refractory cluster headache: a prospective analysis of efficacy over time. *J Neurosurg*. 2021;134(2):393-400.
6. Huber M, Van Vliet M, Giezenberg M, et al. Towards a 'patient-centred' operationalisation of the new dynamic concept of health: a mixed methods study. *BMJ Open*. 2016;6(1):e010091.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Kurt E, Volkers RW, Engels Y, Mulleners WM, Witkam RL, van Dongen RTM. A qualitative study on the long-term effectiveness of occipital nerve stimulation in patients with chronic cluster headache. *Headache*. 2023;63:1458-1461. doi:10.1111/head.14646