

High flow versus ultra-high flow (demand valve) oxygen delivery in cluster headache: A patient experience survey by the Organization for Understanding Cluster Headache-UK (OUCH-UK)

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Cluster headache (CH) is a primary headache disorder characterized by repeated attacks of very severe one-sided pain, which is relatively short-lasting, at < 3 hours, and accompanied by ipsilateral cranial autonomic symptoms and a sense of restlessness or agitation.¹ Oxygen has been recommended for many years,² and is established with a double-blind randomized placebo-controlled study to be effective.³ CH is recognized as an extremely severe form of pain,⁴ so that sufferers seek rapid relief. It has been suggested by sufferers, with limited support in the literature, that ultra-high flow oxygen through a demand valve (DV) may be more effective than high flow oxygen delivered through a mask.⁵ Moreover, DV oxygen has potential cost advantages with reduced oxygen consumption and triptan use, as well as the safety advantage that the flow is not continuous but dependent on inhalation.

Data collection was carried out during 2013–2014 by Mr Peter May then the Organization for Understanding Cluster Headache-UK (OUCH-UK) Trustee responsible for research. No formal approvals were sought since this was an entirely patient initiated, funded, conducted and supported study. OUCH-UK offered members with episodic or chronic CH, through its website (www.ouchuk.org), the opportunity to take part in the study. Since oxygen for CH is provided by the UK National Health Service using standard high flow valves delivering up to 15 L/min, the ultra-high flow (DV) was supplied on loan to OUCH-UK members with an integral Schrader connector. The DV can supply oxygen up to 250 L/min. OUCH-UK volunteer participants already using oxygen for the treatment of CH were asked to treat all their attacks for 2 weeks with the standard high flow device and then for 2 weeks with the DV-ultra-high flow device. Specifically prepared attack diaries, designed by the OUCH-UK Trustees, were filled

in for each attack and returned to OUCH-UK. Participants provided information on their age, sex and diagnosis. They provided, for each attack, the time taken to abort an attack completely. The sample size was determined by the number of DV's OUCH-UK had purchased independent of the commercial oxygen supplier. Data are summarized as means. No formal hypothesis testing was conducted as this was an open label, uncontrolled study.

Twenty-two participants with CH, 14 female, and one with hemicrania continua, returned data from 30 distributed DVs. There were 17 with chronic and five with episodic CH. The age range was 16–79 years with a mean of 49 years. Data were available from 768 attacks treated with standard high flow oxygen and 715 attacks with ultra-high flow-DV oxygen.

The mean typical attack length reported by patients was 90 min untreated and 30 min treated with oxygen. Their mean shortest ever attack was 40 min, and their mean longest attack was 188 min. The mean attack frequency per day was four and the mean maximum attack frequency in a day 7.

The mean time to abort completely an attack using standard high flow oxygen was 36 min, while the mean time to abort completely an attack with ultra-high flow – DV oxygen – was 11 min. Standard high flow oxygen completely aborted 70% (538/768) of attacks. Ultra-high flow – DV oxygen – completely aborted 89% (636/715).

A considerable body of patient-derived data supports a view that ultra-high flow DV-delivered oxygen may be more effective than routine high flow oxygen, the latter being already recommended for the acute treatment of CH. If so, there are opportunities for cost savings, such as reduced triptan use through more effective treatment of attacks with oxygen, and reduced oxygen use, since



oxygen only flows when patients' breathe. Moreover, there are safety advantages, such as oxygen not leaking when the mask is used and the associated fire risk. Our patient initiated and collected data support this position. The ideal way to resolve this question is a carefully conducted, blinded controlled trial. CH patients deserve no less.

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