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The Invisible Invader: A Qualitative Study to Ascertain how  
Living with Cluster Headaches can Impact on a Person's  
Wellbeing and Day-to-Day Functioning

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## **Abstract**

There is paucity of qualitative studies on cluster headaches, particularly ones which use direct quotes from the sufferer's perspective. The aim of this paper is to provide a first-hand account of how cluster headaches can affect an individual's life on multiple levels. Semi-structured one-to-one qualitative interviews were conducted with a purposive sample of 4 cluster headache sufferers from the Lancashire area.

The participants felt their disorder was misunderstood by medical professionals and society in general; various issues with employment were experienced and most of the participants reported they had given up leisure activities and lost friendships through their disorder.

Living with cluster headaches affected virtually every aspect of the participant's lives and the seriousness of this disorder and how it affects a person's overall quality of life deserves more in-depth recognition.

## **Introduction**

When a person experiences pain, it can affect their overall sense of wellbeing, not just the affected body part (Wilde, 2003). People who live with chronic pain may find they need to reconsider many aspects of their life, due to its unpredictable nature (Falvo, 2005). Chronic pain is often a hidden illness and this can make it difficult for others to comprehend and accept its serious and disruptive aspects (Wells, 2000). This can impact on relationships and using the words of Goffman (1990), whereas ‘wise’ people who are part of the sufferer’s life will be supportive, ‘normals’ do not have it within them to convey empathy. One ‘socially invisible disease’ (Lornardi, 2007) which is often underestimated, both by non-sufferers and medical professionals, is living with a headache disorder (WHO, 2004).

According to Latinovic et al (2006), 4.4% of doctors’ appointments are from patients who are concerned about headaches. Headaches fall into 2 categories: ‘secondary’ headaches, which are experienced as the direct cause of an injury, infection or disease; and ‘primary’ headaches, where the headache itself has no identifiable cause (GP-update, 2010). Migraine is the most frequently experienced primary headache (Watson, 2008); whereas cluster headaches are one of the rarest forms and reportedly the most unbearable pain a person could experience (Kernick, 2009; May & Leone, 2003; Bahara et al, 2002). To give justification to this claim, the following is a direct quote taken from a person who was interviewed for this study: *‘An attack causes me excruciating pain on the left side of my face, eye, and head. The pain is so severe it is like a screwdriver gouging my eye. During an attack my eye waters profusely and droops, my nose is bunged up on the left side, I am boiling hot and sweat.’* (Int3:L8-

11). This quote shares first-hand experience of the intensity of pain which is experienced. The pain of a cluster headache does not directly cause the sufferer to die; nevertheless, a few people have been known to commit suicide to be free from it (Barrett & Frey, 2007); hence earning the nickname 'suicide headache' (Dodick et al, 2000; Torelli & Manzoni, 2005). Results from a vast cluster headache survey which took place in the United States reported that out of the 1134 correspondents, 55% had considered suicide and 2.2% had attempted suicide (Rozen & Fishman, 2009).

Despite the pain of living with this disease, research studies on cluster headaches frequently report that sufferers tend to be smokers, and it is often brought into question whether smoking could be a possible predisposing factor (Dodick et al, 2000; Swanson et al, 1994). However, people who have stopped smoking have experienced no reduction in symptoms (Peatfield & Dodick, 2002; Bahara et al, 2002). This study has excluded any further reference to smoking and did not question the participants on their habits. The researcher did not class its inclusion as having any significant relevance in a small qualitative study which is primarily concerned with how this disease can affect the individual's wellbeing and quality-of-life.

Miles et al (2004) suggest qualitative studies have a vested interest in 'invisible pain'. However, with headache disorders, migraine is the most extensively researched (Jurgens et al, 2010; Kernick et al, 2008; Peters et al, 2002); and there have been few qualitative studies which focus on cluster headaches, despite this disease causing a significantly higher level of pain than migraine (Rozen, cited in Gannis, 2010). Silverman (2006) suggests that choosing the correct research method needs to be carefully considered and specifically chosen to allow the researcher to gain the required information; also, time and available resources should be taken into account. The aim of this project was to provide the reader with an empathic understanding into

the lived experience of cluster headaches and how this disorder impacts on the sufferer's emotional wellbeing and daily living. As Denscombe (2003) asserts, if the purpose of a project is to provide detailed information, plus the inclusion of emotional matters, qualitative methods are appropriate; particularly when the potential participants are assessable and could be interviewed in a time and cost-efficient manner. After corroborating with OUCH (UK) to establish an approximate number of cluster headache sufferers who live within the Lancashire area (Appendix 1), the researcher felt confident an adequate sample size would volunteer for this project, without being inconvenienced by lengthy and expensive travel arrangements to the interview venue. The researcher believes that the main aforementioned factors which were suggested by Silverman (2006) and Denscombe (2003) were taken into consideration and deemed a qualitative approach to be the favourable option for this particular study. Additionally, there is a lack of literature which can provide the reader with an empathic understanding of cluster headaches. This further justified the choice of qualitative interviews.

## **Literature review**

### **Chronic Pain**

In the United Kingdom, it is reported that chronic pain affects 7.8 million people (Parliament UK, 2008). Learning to accept the ongoing state of living with chronic pain and the challenging emotions which often accompany it can be a long and difficult process; as no longer being able to take good health and the lifestyle which accompanied it for granted, can leave a person feeling bereft of their old life. It is not just the affected body part which causes disruption, but learning to adapt a lifestyle to fit around the pain (Wilde, 2003). Feeling well in the morning does not guarantee a pain-free day (Taylor & Field, 2003) and this unpredictable element alone can make planning ahead problematic. As a consequence of this, plans may have to be frequently cancelled (Wells, 2000), and considerable frustration can be experienced through trying to cope with restrictions imposed upon everyday functioning (Miles et al, 2004). The freedom which was once enjoyed to participate in leisure and social activities can no longer be taken for granted; as pain can cause the individual to refrain from engaging in pursuits which were once an enjoyable part of their life (McGuire et al, 2008, cited in Valente et al, 2009). As a possible outcome of this, autonomous people often educate themselves about their illness; accordingly, they become experts in their disorder, thus allowing them to have some control over their illness and maintain some quality of life (Magura, 2009). Taking this positive attitude can be beneficial to wellbeing, as the effects of a chronic condition are not only contained within the individual; they are far-reaching, affecting relationships with friends and family (Wells, 2000).

## **Social Support**

In the literature review by Valente et al (2009) several studies which related to the importance of social support in chronic pain sufferers generally agreed that having a well-balanced support system could assist with the emotional upheaval which can be a consequence of living with chronic pain. Developing a chronic condition can be a testing way to measure the strength of relationships and although some people may experience a strong support system, this is not always so (Wells, 2000). According to Goffman (1990) the people who come into contact with a person living with an illness can be classed as either 'wise' people or 'normals'. 'Wise' people include true friends and loving family members who often become educated about the sufferer's condition and will offer invaluable support, both on a practical and emotional level. The inability to control one's behaviours which can result from a chronic condition does not cause a great deal of embarrassment, because 'wise' people are fully aware that the behaviours are symbolic of the illness and understand that they are not the result of a mental disorder or addiction. The same does not apply to 'normals', who may misinterpret a sufferer's behaviours. 'Normals' are those acquaintances that have had little direct involvement in the sufferer's life to any degree or depth. They may prefer to avoid the sufferer altogether and this can result in them having no comprehension of the disorder, nor the desire to become educated about it. Equally, the condition may make them feel un-nerved or embarrassed, which could lead to their insensitivity (Goffman, 1990).

## **Invisible Illnesses**

Living with a hidden illness, in particular one which is rare or has a lack of understanding surrounding it can be exasperating for the sufferer, as other people may



find the difficulties which occur in the sufferer's life hard to accept; because they are unable to see the affliction, they cannot always understand it (Wells, 2000). Some chronic conditions can lay dormant for long periods of time, then a sudden flare-up can occur resulting in uncontrollable behaviours which are not usually part of the person's character; thus, although an illness can be invisible, at other times it can also be greatly visible (Joachim & Acorn, 2000). When behaviours are expressed which are not classed as the 'norm' in everyday society, the sufferer can believe others are labelling them and feel stigmatized (Taylor & Field, 2003).

## **Headaches**

Headaches are classed as a 'socially invisible disease' and can cause some sufferers to feel stigmatised (Lornardi, 2007), despite this being amongst the most common type of chronic pain reported (Parkins & Gfroerer, 2009). According to Kernick (2009), 20% of adults who live in the UK have a headache disorder. Out of every 1000 doctor's appointments, 44 are from patients seeking advice for headaches (Latinovic et al, 2006). It is a common occurrence for people who live with this disorder to receive no specific diagnosis on what type of headache they are actually experiencing (Morgan et al, 2007). As yet, it has not yet been fully ascertained what causes GPs to find headaches such a difficult disorder to treat and correctly diagnose (Watson, 2008); however, as Peters et al (2002) report, doctors only get to spend an average of 8 minutes per appointment with primary headache sufferers in everyday practice; thus an opportunity to gather a deeply informed knowledge base on all headache types is not likely to present itself unless they choose to specialise in the disorder.

## **Migraine**

Migraine affects 6 million people in the UK and the pain is accountable for 100,000 people losing time from employment and education, every working day (Steiner, et al 2003, cited in Watson, 2008). The condition is more prevalent in females, affecting 15% of the female population, compared to 8% of males (Kernick, 2009). Nausea and/or sickness are a common feature and the sufferer can also experience sensitivity to sound and light. The pulsating pain of migraine is further aggravated by movement, causing the person to withdraw into a darkened room and lie down, whenever this is possible (Saper et al, 1992).

Migraine costs in excess of £1 billion per year, purely through the sufferer's inability to work, or work to their usual standard (Kernick, 2009). The condition also has personal costs, as it affects the sufferer's personal quality-of-life. In the epidemiological 'family-impact' study by Lipton et al (2003), last-minute cancellations of family activities, not being able to plan ahead, and becoming argumentative were just some of the main life disturbances which were commonplace among the 389 migraine sufferers and their partners. Similar findings were reported by Ruiz de Velasco et al (2003) from their qualitative study using focus groups and personal interviews consisting of 33 migraine sufferers, 5 relatives and 7 health care professionals. The effect migraine had on family relationships affected some of the participants psychologically, and they reported that being emotionally unstable and unable to participate in social activities negatively influenced their relationships. Some family members admitted that although they were sympathetic, they also felt frustrated and angry about how their loved one's headaches impacted on family life.

Participants related that people who had never experienced a migraine misjudged and underestimated their condition.

Stigmatization can be problematic for serious headache sufferers; virtually everyone has experienced a headache, but often this is at the lower end of the pain spectrum and easily treatable, resulting in some people being unable to comprehend the negative impact that serious headaches can cause. Such people assume the pain they experienced with a minor headache to be comparable; whereas other neurological conditions such as epilepsy and multiple sclerosis (MS) cannot be compared to similar disorders by healthy people. This results in them being unable to down-play the impact of these diseases, whereas the same does not apply to headache disorders and this can be emotionally damaging to sufferers (Lornardi, 2007). The first study to consider that migraine is a condition which is stigmatized consisted of 123 chronic and episodic migraine sufferers who were invited by Park et al (2010) to fill out a Stigma Scale for Chronic Illness (SSCI). When results were compared to those reported by people who lived with neurological conditions including epilepsy and Parkinson's disease the SSCI scores were 'significantly higher' in chronic migraineurs, meaning their condition resulted in them feeling misjudged, criticised or excluded from society (cited in Robert, 2010).

### **Cluster Headaches**

A very different headache disorder, which can leave sufferers feeling misjudged, is cluster headache (CH), which were once previously believed to be another version of migraine (Dodick et al, 2000). Conversely, it is not uncommon for a sufferer to also live with migraines (D'Amico et al, 1996). It was not until 1988 they were recognised by the International Headache Disorder Society (IHS) as being a disorder with their

own status (Dodick et al, 2000). CH belong to a section of primary headaches known as 'Trigeminal Autonomic Cephalalgias' (TACs) and this particular group all share similarities, which can make a precise diagnosis problematic (OUCH UK, 2010). Symptoms include restlessness, unilateral pain, evident perspiration and uncontrollable tearing of the eye. The nostril is also affected through either running or feeling blocked and is experienced on the same side as the pain. CH is divided into 2 types: episodic (ECH) and chronic (CCH). ECH are the most common type and experienced by 80-90% of sufferers and bouts are experienced approximately twice every year and last in the region of 4-12 weeks; attacks, which can strike some sufferers several times per day, then lay dormant until the next bout. CCH are experienced by the remainder of sufferers and daily pain can be undergone for periods in excess of 1 year (OUCH UK, 2010). Although some people can find their pain is alleviated for a while, this is short-lasting and by classification does not exceed 1 month (ICHD-II, 2004).

CH affects approximately 0.14% of the population (OUCH UK, 2010) and the pain intensity is estimated to be 100 to 1000 times worse than migraine (Rozen, cited in Gannis, 2010); what's more, female sufferers assert it would be preferable to go through childbirth than experience another attack (May & Leone, 2003) and men state they would find passing a kidney stone more favourable (Gannis, 2010). In the prospective study by Torelli & Manzoni (2003) 42 patients who were in bout, were asked to rate the pain of CH using a Visual Analogue Scale (VAS) which consists of a 10cm pain scale, where 10 is the most extreme form of pain imaginable. Only 6 people rated their pain to measure below 8cm. Hence, the pain can cause extreme agitation and this is a distinct characteristic of CH (Ertsey et al, 2004; Blau, 1993) and reported by the majority of 230 sufferers who participated in Bahara et al's (2002)

study. Nevertheless, it is still not generally accepted that serious forms of headache can have gravely debilitating consequences on the sufferer's life, and fearing that severe pain could strike at any time can disrupt everyday routines, and have incredibly disruptive repercussions (Lonardi, 2007). Professor Goadsby, a leading neurologist in headache disorders (Henderson, 2008), reports that the invisibility of the disease can cause people, including medical professionals, to question its authenticity. However, he responds to this by citing '*...you can't see air...see gravity.*' (Goadsby, 2007, p1)

CH was once believed to be a disease significantly more prevalent in males, but over the years the number of females with the disorder is increasing; however, ratios are not exact and vary from 7:1 to 2:1 (OUCH UK, 2010). It is still not clear why the gap is closing; however, one suggestion put forward by Rozen et al (2001) is that women could have been wrongly diagnosed with migraine in the past. This appears a plausible explanation because out of the 32 female CH sufferers who participated in their study, a higher percentage experienced 'migrainous symptoms' compared to the 69 male participants, and migrainous symptoms were once believed to hold no significance in the cluster profile (Rozen et al 2001).

## **Behaviours**

The agitated behaviours which are common in cluster headaches stand alone when compared to other headaches disorders outside of the TAC group (OUCH UK, 2010), and the sufferer can exhibit a demeanour which holds no semblance to their usual character. Rocking, crying, punching and squeezing the site of pain; hair tugging, swearing and behaving in an aggressive or destructive manner are a reaction to the pain and not a sign of the sufferer losing their mind. It is also possible that the person has little or no conscious awareness of what they are doing (Lay, 2002). Although

such actions may seem peculiar to non-sufferers they are not a rare occurrence to a person afflicted by CH. This is substantiated by the findings from Rozen & Fishman's (2009) survey consisting of 1134 CH sufferer's where half of the participants reported that they hit themselves during an attack. Adding to this, among the behaviours reported by 42 ECH sufferers who filled out questionnaires for Torelli & Manzoni's (2003) research, sufferers were prone to irritability and crying, also agitated movements and the need for solitude.

### **Misdiagnosis**

Although CH is an unbearable disorder it is frequently misdiagnosed as a different condition, or only diagnosed after the sufferer has lived with the disorder for a lengthy period of time (Kernick, 2009; Kernick et al, 2006; Vliet et al, 2003). In a quantitative study by Vliet et al (2003) consisting of 1163 CH sufferers, the shortest diagnosis was 1 week and the longest took a staggering 48 years. Before receiving a proper diagnosis, some respondents had been diagnosed with sinusitis – resulting in a few being referred for unnecessary operations. A number of participants had been referred to dental practices and others were diagnosed with migraine. Blau (1993) also reported that 2 of the most common complaints which CH are misdiagnosed for are sinusitis and migraine. The National Institute for health and Clinical Excellence (NICE) is currently working on an up-dated document to assist medical professionals with diagnosing and treating different headache disorders; it is intended this will be published and available in December 2012 (NICE, 2011). Providing doctors with crystal-clear details of the different symptoms experienced in headache disorders could save their patient a great deal of unnecessary suffering which is experienced through misdiagnosis (Thomas, 2008).

Headache disorders are not an ailment which are given a great deal of taught hours in medical schools; overall, student nurses are unlikely to receive any training on headache disorders and other medical students can receive as little as 1 hour's education (Thomas, 2008). 'Lifting the Burden' which is a collaborative affair between headache societies and the World Health Organisation Alliance, aims to address such issues, and advocate that education is the key to help healthcare providers become knowledgeable and confident in recognising different headache disorders (Watson, 2008). On the whole, it can be problematic for medical professionals to make an initial diagnosis of CH, because as discussed earlier, they have similarities to other TACs. Hence, it is vital that a person who is living with the symptoms of CH asks their doctor to refer them to a neurologist who has a special interest in headaches, because through careful questioning a diagnosis of headache type can then be made (OUCH UK, 2010).

## **Referrals**

According to Latinovic et al (2006) 2% of headache sufferers are referred to neurologists. However, gaining access is not a straightforward process (Morgan et al, 2007) although 'red flag' guidelines are available to doctors to assist with them making the decision of whether their patient's headache symptoms warrant further investigation (GP-update, 2010). Morgan et al (2007) aimed to discover more about the referral process, by holding semi-structured qualitative interviews with 20 GPs from 13 practices, including both the affluent and poorer areas of London. At some point in their career, all the doctors admitted to referring patients who had on-going headaches and remained convinced there was an underlying cause. However, in the year before this study, 10 GPs had made no neurological referrals for headache, 5

made 3 referrals and 5 made 1-2. Referral rates varied greatly and were influenced by the doctor – patient relationship and the doctors’ personal attitude toward their own capabilities. Availability of facilities was also a factor; because when headache clinics and doctors who specialised in headaches were readily available, doctors were more likely to refer patients to these services rather than to specialist neurologists as they did not have lengthy waiting lists. Most doctors believed a patient had a ‘right’ to see a specialist, but some – although in the minority – felt their patients were undermining their knowledge; hence, those who had a strong belief in their capabilities concerning neurological complaints were unwilling to refer patients, despite their pleas for help. Those who were least likely to refer, also stretched their beliefs by refusing to give consent to patients who requested permission to pay and go private, if they believed their anxieties were unfounded. Some doctors admitted they did not possess the ability to give a definite diagnosis and were happy to make referrals, asserting the earlier the better. Doctors with a cautious nature who were primarily concerned with their patient receiving a definite diagnosis referred them to specialists and several doctors believed that referrals should be made if the patient remained certain there was an extremely serious cause which was creating their headaches (Morgan et al, 2007). These anxieties over headaches were commonly referred to by participants in Peters et al, (2004) and Leiper et al’s (2006) qualitative studies; however, headaches specialists report they are rarely caused through a grave underlying condition (Kernick et al, 2006). Nevertheless, it is paramount that sufferers of CH are referred to specialists and prescribed specific medications to help them to deal with the pain (Blau, 1993).



## Orthodox Treatments

The pain of CH usually occurs very abruptly and renders medications which need to be absorbed into the gut virtually useless in aborting an attack (Bahara et al, 2002). In a study of 246 CH sufferers in Germany, injectable sumatriptan and oxygen were the most effective form of pain relief for CH sufferers (Schurks et al, 2006). The injection brings the quickest form of pain relief, but despite this being the ‘only licensed abortive’ for CH, medical professionals will not always willingly prescribe it because of the expense (OUCH UK, 2010). The cost of sumatriptan is a huge issue for health care providers, but due to the difference it can make to a sufferer’s life, it could be classed as unethical to withdraw or refuse it (Bahara et al, 2002). Another issue with sumatriptan is it has not been medically tested on people over 65; hence, it is at the consulting doctor’s discretion and with the support of his/her colleagues, whether an individual over this age could continue to use it. However, Goadsby (2007) asserts that, the continuation of this treatment ‘is not an issue,’ providing the patient has a healthy heart– and this stipulation is relevant to a person of any age. Oxygen, which also has proven efficacy for aborting CH, is not freely available in the UK on the NHS, also because of expense (Bahara et al, 2002). In England, it is estimated that 85,000 people are supplied with home oxygen for a number of acute and chronic health conditions – 60% who live with Chronic Obstructive Pulmonary Disease, which in total costs the NHS £110 million (Okosi, 2008). The date was set as February 2006 for new guidelines to be introduced to bring bills down; hence, re-assessing supplies was necessary (Henderson, 2005). In the first year of these guidelines being implemented, the NHS North East Essex home oxygen service saved £490,000, through cutting ‘inappropriate oxygen prescribing’ (Fordham et al, N/D).

With intractable CH where no medications bring relief, medical procedure are available, such as dihydro-ergotamine (DHE) which is administered intravenously over several days (Dodick et al, 2000). Out of 54 patients who were assessed after the procedure, after an average of 6 days in hospital, 100% were relieved from pain and this status was maintained by some of the sample after 1 year (Mather et al, 1991, cited in Dodick et al, 2000). Nevertheless, side effects of some medical procedures can have far-reaching consequences; thus, Occipital Nerve Stimulator Implants may be a viable option for some people, due to them requiring a less harsh procedure, although research is still ongoing (OUCH, 2010).

### **Limitations on Daily Living**

People who live with CH can experience serious and ongoing disruptions to their overall quality of life. D'Amico et al (2002) assessed 34 ECH and 22 CCH sufferers to examine quality-of-life issues faced by this group, compared to the general Italian population. They reported that although there was no remarkable difference in the 2 groups' ability to physically function or in their vitality levels, there was a significant debilitation recorded in the CH sample on their ability to function socially. Their general health, mental health and emotional wellbeing also showed a 'clinically significant' difference which affected their ability to fully perform on an employability and social level. This was consistent between both the ECH and CCH groups. This study also discovered that regardless of receiving correct medications, some sufferers still found their ability to function severely affected. The research by Jurgens et al (2010) corresponds with this. In their sample a subgroup of 22 ECH sufferers were currently out of bout, yet despite this, some still reported feeling debilitated – although not to the extent of those with active ECH and CCH. It is

possible the fear of pain and the negative effects it had on multiple areas of their lives, resulted in lingering thoughts of life disruption, even when a bout had finished (Jurgens et al, 2010).

Jensen et al (2007) conducted semi-structured telephone interviews with 85 participants to ascertain how CH impacted on their ability to function socially and how the disease affected their employment. Results were compared to a control group of 848 subjects with a similar background, all of whom had been diagnosed with various headache disorders; and with the exception of 1, this excluded CH. Virtually every aspect of daily living had been affected by CH, and sufferers reported feeling limited in what they could do. Lifestyle changes were also a major challenge, with people reporting they had had to adapt their lifestyle over the past 10 years to live around their disorder. Sleep patterns, independence and employment issues were all significantly impacted upon; with leisure activities, holidays and drinking alcohol just 3 of the enjoyable pursuits given up through the impact of CH. In Schurks et al, (2006) cohort study of 246 CH sufferers, the majority reported alcohol was a trigger for a cluster attack.

### **Complementary and Alternative Medicine (CAM)**

When people live with a condition which is negatively affecting their ability to fully function and contend with everyday activities, despite receiving orthodox treatments, they may feel it is worthwhile turning to complementary therapies. This is particularly relevant to those who live with chronic conditions which are manageable, rather than curable (Sharma, 1995). However, in the 2 articles which were reviewed on the effectiveness of CAM on CH, the results were not very hopeful. In Bahara et al's study (2002), from a sample of 230 CH sufferers, 63% had paid to see an alternative

therapist. Chiropractic treatments, acupuncture and physiotherapy were some of the practices visited, but none of the sample experienced any noteworthy success with their chosen treatment. In the smaller sample of 29 CH sufferers studied by Rossi et al (2008) there was some limited success, with 28% reporting some degree of relief. However, the placebo rate is reported to be about 30%, hence these figures could possibly be through belief in the treatment (Rossi et al, 2007). Nevertheless, as mentioned previously, quality of life does not necessarily return to normal for someone who lives with CH purely through being prescribed the correct medications; hence, it is understandable that some sufferers are willing to try an alternative treatment to try to get their life back on track.

## **Method**

### **Design**

Qualitative methods of enquiry were chosen for this study, to examine previously elusive areas and bring greater understanding to a subject which may have been previously misunderstood (Peters et al, 2002). Articles which contain viewpoints directly from a CH sufferer's perspective are rare, and research studies using survey methods cannot provide a comprehensive first-hand account on what living with the disease entails (Loder, 2005). One-to-one qualitative interviews were chosen for this study to gain a rich data set. As a result, the researcher could report findings directly from the individual's perspective (Peters et al, 2002). The participants who applied to be interviewed for this study were aware that the interviewer was a member of the Organisation for the Understanding of Cluster Headaches – OUCH (UK) and this could possibly have affected the interview process, as they may have felt more at ease with discussing more sensitive issues. For further information on OUCH (UK) see Appendix 2.

### **Participants**

3 males and 2 females originally responded; however, 1 withdrew prior to interviewing due to adverse weather conditions and did not respond to the alternative of participating through a postal interview. The remaining 4 participants who volunteered for this study were residents of the Greater Manchester/Lancashire areas and members OUCH (UK) who responded to a website advertisement (Appendix 3). For this purposive study, it was a requirement that each participant was over the age of 18 and had been previously diagnosed by a neurologist as having cluster

headaches. This was stipulated, as the accuracy of the research results were dependant on the sample consisting of cluster headache sufferers only. The 4 participants consisted of 2 males and 2 females. The first participant was female and had taken early retirement; she had experienced ECH for 35 years. The second female participant worked part-time and had lived with CCH for 4 years. The third participant was no longer able to continue doing paid work due to his CCH, which he had suffered from for 19 years. The final participant had set up his own business and worked from home, his ECH had started 6 years previously.

## **Materials**

As suggested by Robson (1993) open-ended questions were used due to their flexibility in gaining information and their non-leading nature. The main topics covered can be found in the participant information sheet (Appendix 4). The majority of questions arose through the researcher analysing mostly quantitative research articles and noting that although the issues raised were vital in bringing awareness to the difficulties faced by CH sufferers, they could be of further benefit if the answers to some of the questions could be elaborated upon qualitatively. Some qualitative articles were also of benefit to put the questions together, but these mostly focused on headaches in a more general sense. The following studies were particularly useful for inspiring the questions used in this piece of research: Bahara et al (2002); D'Amico et al (2003); Ertsy et al (2004); Jensen et al (2007); Leiper et al (2006) Rossi et al (2007) and Vliet et al (2003).

## **Procedure**

Permission was requested (Appendix 5) to place an advertisement on the OUCH (UK) website and granted by the co-ordinator (Appendix 6). The participants, who

contacted the researcher via the University of Salford email address, all met the selection criteria and upon request were emailed participant information sheets. Each participant was advised to take their time to read through the information and email the researcher should they have any further enquiries or would like to make preliminary arrangements for an interview. Each participant made contact within 3 weeks and mutually agreeable interview dates were arranged to take place in a comfortable office at the University of Salford. Interview guides were emailed to the participants at least 7 days before interviews commenced (Appendix 7). The interviews were semi-structured with the intention of gaining a deep insight into the lived experience of CH and to help with answering the overall research question, which was formed to ascertain how living with CH impacted upon the sufferer's life and wellbeing as a whole. Reflective listening skills and non-verbal communication skills were essential in this study, as these give participants reassurance that they are being listened to and can encourage 'expansion' of replies, as interest is being conveyed (Merry, 2002). Toward the end of the interviews, participants were invited to chat about any issues they regarded as important, but had not been covered. The interviews lasted an average of 37 minutes and were digitally recorded; this excluded participant 4 who arranged with the researcher to respond to the questions by post, due to the sudden change in weather leaving travelling conditions hazardous. Consent forms and written assurance concerning confidentiality issues and an SAE were sent and a detailed response to the questions was received via the University of Salford address, along with a signed consent form.

## **Ethics**

Ethical approval was gained from the University of Salford Research Governance and Ethics Committee for this study to take place. The researcher's supervisor Julie Jones, who has a special interest in chronic pain, was present throughout each interview. This gave each participant further assurance their wellbeing would be fully cared for if they were to experience any distress. Prior to the recording of interviews, each participant was verbally informed they had the right to withdraw at any time, plus could refuse to answer any question which could cause discomfort; a consent form (Appendix 8) was then signed. After the interviews, a helpline phone number for CH sufferers was given, in case the participant experienced any upset after they had left the premises. All other ethical issues which are detailed in the participant information sheet were strictly adhered to.

## **Analysis**

Each interview was digitally recorded and transcribed verbatim. All identifiable features were removed and each participant was forwarded a copy of their individual transcript, which allowed for them to make any amendments, before thematic analysis commenced. Analysis was undertaken between January and March 2011 to identify themes which related to the participants' lived experience of CH. The 6 steps of thematic analysis, as recommended by Braun & Clarke (2006) were used as guidelines for the process of building themes. The researcher became familiar with each interview by listening to them several times and taking notes. Familiarisation was further enhanced by writing out the data verbatim, typing up and re-reading several times. Segments were coded and re-coded throughout the familiarisation process until broad themes were established. Themes were then narrowed down and



subthemes formed to cover specific topics which were common to the transcripts. To justify their validity, the findings were checked against existing studies (Maykut & Morehouse, 1994).

## **Results and Discussion**

The following 3 themes and the accompanying subthemes were discovered after interviewing 4 people who live with cluster headaches, to ascertain how living with the disorder impacted upon their life and wellbeing. A table of themes and subthemes can be found in Appendix 9.

### **Theme 1: The Patient's Perspective**

A number of different aspects were reported which related to consultations with doctors. These were separately titled under 7 subthemes to cover the full range of difficulties.

#### **Misdiagnosis**

3 of the participants were diagnosed with various disorders:

*... 'I saw a local neurologist and, erm, he told me I had cluster headaches but I didn't really have them, because women don't get them.'* Int2: 25-26

*'...and when I went the doctor said 'oh, you've only got migraines'... one specialist said it was my sinuses, so I had an operation to clear my sinuses out'* Int3: 42-43&60-61

Being misdiagnosed was a common feature and whilst waiting for a correct diagnosis, repeated visits to the doctor resulted in participants being diagnosed as having

sinusitis, neuralgia, migraine and tension headaches. Conversely, 1 participant was given a confusing diagnosis by a neurologist; she was informed that although she did have CH, she actually did not, because it only affected men. CH was once known to be a disorder which affected significantly more males, but over the years it has become recognised that many women also live with this disorder (Rozen et al, 2001). Blau (1993) reported that migraine and sinusitis were the 2 most common medical conditions which CH are mistaken for and this appears to have remained consistent over years. Furthermore, Vliet et al (2003) reported that 17% of their sample had been diagnosed with migraine and 21% as having sinusitis; 33% of the sample was referred to an Ear, Nose and Throat specialist, and 12% were subjected to unnecessary sinus operations.

### **Fear of sinister cause**

Due to being misdiagnosed, the pain remained and 3 participants feared there was an underlying serious cause:

*'And scared as well... the longer that you don't know what it is... I had this severe pain in my head and you automatically think it's something sinister.'* Int2: 43-44

*'Well, someone I used to work with, their wife had a brain haemorrhage and the symptoms I had were exactly what he said his wife had and I started thinking all sorts, I've got brain haemorrhages, it goes through your mind, what's wrong with me?'* Int3: 54-57

Although the participants had been prescribed medications, they had no impact because they were not for CH. Living with severe pain which was not responding to medications caused the participants a great deal of anguish, as they believed it had an

underlying sinister cause. Although no CH studies could be found to provide further evidence of these fears, in the mixed primary headache study by Leiper et al (2006) concerns about brain tumours, haemorrhages and strokes were reported; what's more, doctors who were interviewed by Morgan et al (2007) stated that these worries were common in headache patients.

### **Problems with referral**

3 participants found it particularly problematic to get a referral to a specialist:

*'...absolutely horrendous attacks and I was pleading with him... I really can't cope any longer... its only when I got to the desperate stage they sent me to an ear, nose and throat specialist'* Int1: 82-83, 88-90

*'I had to keep fighting to get a referral to Queens Square in London, because they'd been recommended to me.'* Int2: 27-28

Despite feeling they could no longer tolerate the pain, being referred to a headache specialist was not a straightforward process for 3 participants and 2 of these resorted to paying privately for a referral – 1 after the ENT specialist advised her doctor to send her to a neurologist as she did not have sinusitis, which had been her doctors on-going diagnosis. Morgan et al (2007) reported that receiving a referral was mainly dependant on the doctor's personal attitude toward their capabilities of treating headaches. When GPs are supplied with the modernized headache literature by NICE, which should be available in December 2012 (NICE, 2011), maybe people who are

suffering from undiagnosed CH will be referred without their distress being added to, by having to 'fight', plead or pay privately for a referral.

### **Delay in correct diagnosis**

3 participants had to endure untreated pain for an excessive amount of time:

*'I was diagnosed after fifteen years.'* Int1:L312

*'I went for nine years after my first attack before I was diagnosed with cluster headaches.'* Int3: 35-36

As discussed in the literature review, diagnostic delay is not uncommon with CH, and the length of time it took the participants in this study to be diagnosed ranged from less than 1 month, up to 15 years. This emphasises the difference that being sent to a neurologist who recognises CH symptoms can make. These delays were consistent with the research in the literature review by Vliet et al (2003), where over 50% of participants had lived with CH for over 3 years before being diagnosed.

### **Doctor lacks understanding**

When the participants were finally diagnosed, 3 felt the serious impact that CH had on their lives was not recognised by doctors:

*'None at all... every time I go to the GP, even if it's only to get my repeat prescription refilled, ... I'm always in a state of anxiety because whilst my GP is actually really nice... has lots of empathy, she doesn't really understand what cluster headaches are'.* Int1: 209-212

*'No, no, no, erm, so I think, I do think that they really lack any understanding or ability to do anything.'* Int2: 109-110

However, it is important to add that 1 participant had a very good relationship with his doctor:

*'...my experiences appear to have been comparatively good. However, that is mainly due to me being blessed with a GP who does not allow his ego to get in the way of pursuing the correct solutions and who is prepared to admit when he is out of his depth and take appropriate advice.'* Int4: 162-166

For 3 participants, their doctors did not appear to have an adequate understanding of how CH impacted on their lives. Although no CH studies could be found to substantiate this, these views remain fairly consistent with qualitative studies which have examined issues faced by sufferers of other primary headaches. Although the majority of participants in Leiper et al's (2006) study were happy with the care they received, others found their doctor to be 'dismissive' or 'disinterested'; furthermore, Peters et al (2004) reported that some of their sample believed their doctors were not interested in learning how headaches impacted on their life. Watson (2008) asserts that doctors find headaches difficult to treat adequately; hence, sufferers can be viewed as 'heart-sink' patients, because of the complications which can be faced with treating them, resulting in a break-down of the doctor – patient relationship (Christie & Hoffmaster, 1986).

### **Doctor needs educating**

All participants believed that doctors in general did not have enough knowledge to deal with CH effectively:

*'They just say then why don't you contact your neurologist. But when your neurologist is 200 miles away it it's not that simple.'* Int2: 166-168

*'Even the works doctor knew nothing about cluster headaches; he didn't show any interest at all, so really it's the GPs that want educating in this.'* Int3: 166-168

The participants found that their doctors did not withhold satisfactory knowledge to assist them through difficult times and 2 were frequently told to contact their neurologist when problems occurred. However, this dismissive attitude only added to their frustration, as their neurologists were based in London; plus doctors must be aware that waiting lists to see specialist neurologists are not short. The participant who had reported problems with his employers' doctor also related that despite suffering from CH for 19 years and sharing his neurological reports with his regular doctor, she still referred to his disorder as 'migraine'. This showed not only a lack of understanding, but also the inability to recognize the distinct differences between these disorders. The issues concerning doctors and headache care is being addressed (Peters et al, 2002). More doctors who have a special interest in headaches are advocating the impact they can have on people's lives by meeting with postgraduates and sharing their knowledge (Watson, 2008). Furthermore, the Royal College of General Practitioners (RCGP) aims to form an alliance with headache organisations, with the intention that 'educational initiatives' will be offered to medical students and GPs to encourage them to gain more understanding into headache disorders (Kernick, 2009).

### **Patient becomes expert**

All of the participants became an expert in CH:

*'...I'd made him uncomfortable because I knew a lot about my condition and he knew nothing and I got the impression he just wanted me to leave, you know.'* Int1: 243-245

*'It was 3 years before I received the correct treatment, and even then that was only as a result of my own research.'* Int4: 83-84

The participants became extremely knowledgeable about CH and 1 participant put her experience and knowledge to use by working on the OUCH (UK) helpline, allowing her to support other sufferers [discussed after interview]. Leiper et al (2006) also discovered that many people in their sample became very knowledgeable about headache disorders. When a sufferer of a chronic condition becomes educated about their medical disorder, in areas such as how to personally deal with symptoms and make decisions into what treatments work best for them, they are taking a positive and autonomous attitude. This can result in the sufferer feeling their illness has less control over their life (Magura, 2009).

### **Theme 2: Impact of Pain and its Management**

The impact of pain and its management was divided into 7 subthemes to cover how the pain affects the person as an individual and also to report the difference that taking the right medications can make.



### **Experience of pain**

CH is known to be the most excruciating of headaches:

*'...the pain of cluster headaches is so bad that you just can't believe you're not going to keel over. [Laughs] You think your body cannot take this amount of pain without something happening, a stroke or a heart attack.'* Int1: 41-43

*'I would describe going through an attack untreated as unbearable.'* Int4: 98

The participants established that the pain experienced in CH was agonising and their statements expand on aforementioned comments from headache specialists in the literature review, plus the study by Torelli & Manzoni (2003). The participants in their research were asked to rate their pain on the VAS scale, where 10cm is classed as the most unbearable pain imaginable; on average, the participants rated their scale of pain to measure 9.17cm.

### **Sleep**

Sleep disturbances affected all the participants:

*'I've never had a proper night's sleep for nineteen years.'* Int3: L16

*'During a bout I will normally be woken approximately an hour to an hour and a half after having gone to sleep.'* Int4: 27

The intensity of pain affected all the participants' sleep patterns; this is in keeping with other CH studies, which report sleep disturbance to be notorious in sufferers. 100% of the female sample and 91% of the male sample in Rozen et al's (2001) study

found falling asleep would offset an attack when they were in bout. Bahara et al (2002) reported that 73% of their participants were woken by the pain.

## **Moods**

All participants reported dramatic changes in their moods when struck by the pain:

*'It's almost like my character changes, I become this impossible person that's quite rude and not very nice to be near.'* Int1: 589-590

*'Yeah, I am very irritable and bad tempered; the slightest thing makes me flare up.'*  
Int3: 27-28

When experiencing CH, participants felt their moods changed. Becoming irritable, abrupt, rude, bad tempered, frustrated and depressed were the most common words used to describe how CH impacted on their emotions; 1 participant reported that his moods made him feel 'ashamed' and 'guilty', because he worried they made him difficult to live with. These reports of mood swings are supported by Torelli & Manzoni (2003) who related that 28.3% of their sample experienced irritability; Jurgen et al (2010) found 56% of CCH sufferers and 27% of ECH had 'depressive syndrome'. No other literature could be found to expand on CH and moods, but similar results were reported by Ruiz de Velasco et al (2003) where migraineurs reported feeling aggressive and emotionally unstable. Further to this, Lipton et al (2004) reported 50% of their migraine sample admitted to becoming argumentative.

## Behaviours

All 4 participants reported that the pain of CH had affected their behaviours and as a result had caused a degree of mortification at some point in their life:

*'Being caught somewhere in public having an attack and the embarrassment of it and the pain and the fact that you just can't function at all... people look at you as if you are drunk or as if you're... mentally... unhinged'. Int1: 292-293 & 306*

*'I've bruised my hand now before because I've hit my eye with it, I, erm, I've banged my head against the wall, just... it's as though you just go into some kind of trance and you don't know what you're doing and until that pain goes you, you're just not fully in charge of your actions and so it's really embarrassing.' Int2: 260-263*

High levels of pain caused the participants to display uncontrollable behaviours which were alien to them outside of a cluster attack. Although embarrassment was a common emotion, it was experienced in different ways. Whereas 2 participants hated being struck by the pain when out in public, due to fearing their unmanageable and agitated behaviours were being misjudged by passing strangers, 1 preferred to have an attack in front of strangers, rather than at work; because strangers 'did not matter', whereas work colleagues had to be faced on a regular basis. The last participant reported that embarrassment had developed into anger, because of what the disease was doing to him. Displaying agitated behaviours is supported by other CH studies; these behaviours were experienced by 88.1% of Torelli & Manzoni's (2003) participants and 93% of Bahara et al's (2002) sample; Further to this, 50% of Rozen & Fishman's (2009) survey reported that they hit themselves during an attack.

### **Aborting an attack**

Alleviating the pain in as short a time as possible is paramount and being able to abort an attack gave each participant some control over the pain and enhanced their quality of life:

*'...I can even inject in public if I have to, you know, erm, it's only ten minutes, ten minutes is all I have to survive before I become normal again.'* Int1: 321-323

*'Oxygen is my first port of call during every attack. By combining oxygen along with an imigran injection I can normally abort an attack in approximately 20-30 minutes.'*

Int4:106-107

The 2 participants who had CCH had undergone medical procedures to try to gain some longer-term pain relief; but as with the ECH sufferers, they were also dependant on the usage of oxygen and sumatriptan injections to abort an attack. The successful usage of these 2 medications is validated by Schurks et al's (2005) study, where the most successful and favoured treatment for CH was sumatriptan injections, which were used by 81.2% of the sample and oxygen, which was successfully used by 71.1%.

### **Fear of medication withdrawal**

When a sufferer of CH finally finds a treatment which brings them relief from pain, it is understandable that the threat of having it stopped can be a great source of anxiety.

This was experienced by 3 participants:

*'...but that's my next biggest worry because obviously at the moment it's the only drug that's licensed for the treatment of cluster headaches, but it's only licensed up to sixty five.'* Int1: 556-558 [discussing sumatriptan injections]

*'I forgot to mention I'm on oxygen as well and [X] health authorities are trying to get people off the oxygen...through the budgets...'* Int3: 384-385 & 387

Age and budget cuts were a concern for 2 of the participants, through the possibility that these factors could contribute to having their treatments withdrawn. However, Goadsby (2007) reported that providing the patient had no other health problems, age alone would not be a sufficient reason to withdraw sumatriptan injections, which is reassuring news for that age group. Participant 3 was fortunate and did not have his prescribed oxygen stopped, but as reported in the literature review, new guidelines were introduced where specialist teams would assess each individual who required home oxygen, to rate if their needs were appropriate to warrant its supply. As participant 3 quoted: *'The health authorities need to be educated as well because oxygen is a god send to cluster headache sufferers.'* [L398-400] Participant 3 further added that watching some video footage [available from OUCH UK (2011)] of people having a cluster attack could be educational for teams of assessors. Another participant was deeply concerned her treatment would soon be stopped, through having trouble with her veins, meaning DHE may no longer be a viable option, due to it being administered intravenously. In Mather et al's (1991) study 83% of ECH and 39% of CCH sufferers had maintained a pain-free status after 1 year of receiving this treatment (cited in Dodick, et al 2000). With this woman it benefitted her for 8-week periods, and the difference it made to her life by having these pain-free periods could

not be underestimated. Furthermore, she was 1 of 2 participants who reported that prior to receiving treatments (hence, having no control over the pain), on some occasions, fear about leaving the house had been experienced.

### **Complementary and Alternative Medicine (CAM)**

All 4 participants revealed they would try anything to be free from the pain of CH. As a result, a number of alternative treatments were tried:

*'...acupuncture and I can't actually say it did any good and considering some of the things they told me at the time which then turned out to be completely bogus, because I didn't have sinusitis, you know, they were obviously making it up as they went along.'* [Laughs] Int1: 197-200

*'I've tried acupuncture, the first course of acupuncture seemed to help slightly... tried physiotherapy... Bowen Technique... Chinese head massage – that didn't work [laughs] so nothing worked really.'* Int3: 197,202,215, 228-229

All participants resorted to trying CAM in order to experience a reduction in pain; physiotherapy and acupuncture were the most commonly tried CAM. No success was found with the variety of CAMS which were used, which reflect the results reported by Bahara et al (2002) where 63% of their sample had paid to see an alternative therapist; 40% went for acupuncture and a minority for physiotherapy and no evidence was reported that any CAM could provide stable pain relief.

### **Theme 3: Overall Disruptions to Life**

The final theme covers how living with CH can touch on multiple parts of a person's life. The main disruptions which were experienced by the participants were put into 8 subthemes to ensure the full ranges of difficulties were covered.

#### **Employment**

Each participant had experienced disruptions to their career:

*'I'm part time now, erm, which... it's annoying that that I've had to do that...'*

Int2:159-160

*'In the end I had to give my job up. It really broke my heart because I really enjoyed the job I did.'* Int3:150-151

All participants reported different disruptions to their career. This was particularly problematic to 2 participants, as 1 had no option but to leave a job which he thoroughly enjoyed and another had her flexi-time stopped. This resulted in her no longer being able to work full-time and having no choice except to reluctantly agree to cut her hours to part-time. 1 participant took the opportunity to retire early and the other became self employed and found working from home to be greatly beneficial. These changes to working patterns are validated by Jensen et al (2007); employment was lost by 16%, early retirement taken by 8% and out of the 54 who still worked, 27% had adapted their work pattern because of CH.

### **The worry of pain**

Living with an unpredictable illness can mean the impact it has on the sufferer's life is never far from their mind:

*'I think about it every single day of my life because I think about have I got an imigran injection in my bag before I leave the house.'* Int1:173-175...

*'When either in bout or on the fringes of a bout... We never go out for dinner because it ends up playing on both our minds, and we end up sat there looking at each other wondering when it is going to happen and not if.'* Int4: 318&325-327

Even when pain was not being experienced, all the participants felt they had to be on their guard and prepared for an attack. This impacted upon each person to varying degrees. The worry of facing a cluster attack either prevented individuals from participating in activities; or made them plan in advance by having a supply of medications to hand. To a degree, these findings give further evidence to Jurgen et al (2010) who postulated that the reasons 13% of Jensen et al's (2007) sample still felt their life held certain restrictions when they were out of bout, was through the fear of pain striking; and the serious way in which it affected their life, resulted in lingering and deep-rooted concerns.

### **Inability to plan ahead**

Due to the unpredictable pain of CH, it can be particularly problematic for sufferers to plan ahead; this was reported by 3 participants:



*'...the main impact on your life is losing your freedom that you've had, your ability to plan ahead...' Int2:251-252*

*'I am unable to plan for today, let alone tomorrow or next week' Int4:308*

The participants reported that the freedom to make plans for the future was impeded upon due to the worry that a CH would strike. No study specific to CH could be used to substantiate this, but Lipton et al (2003) reported 32% of their migraine sample could not plan ahead for the fear of having a migraine attack.

### **Social/Leisure activities**

3 participants reported that some activities which were once enjoyable had become a thing of the past:

*'...I mean I don't I don't go out nearly as much as I used to do, erm, and when I do, it's because I can't drink anymore either.'* Int2:180

*'...we don't do a lot of the things we used to; we enjoyed going to the theatre a lot, out for meals, going on weekends away...' Int3:315-318*

Living with CH had a detrimental effect on social and leisure activities. Visits to the theatre, outdoor pursuits and socialising in general were adversely affected. This is in keeping with D'Amico et al (2003) who reported that 59.1% of their sample had stopped participating in social and leisure activities. Being unable to drink alcohol

was reported by 2 participants, due to it being a trigger when they are in bout; 90% of Bahra et al's (2002) sample also reported alcohol to bring forth an attack.

## **Holidays**

The planning of holidays needed to be carefully considered by all of the participants:

*'...with travel insurance, they won't cover me for cluster headaches.'* Int1:475-476

*'With regard to the booking of accommodation, we have to incur a financial impact and pay a premium rate for accommodation that can be cancelled at short notice...'*

Int4:327-329

Holidays were a specific leisure activity which was affected and each participant worked around their difficulties in different ways. These ranged from always travelling to the same place, where the participant found the staff to be knowledgeable and sympathetic, to paying a financial premium to safeguard against cancellations. Packing a large supply of medications was also needed due to CH not being covered by travel insurance. Changes to holiday habits were reported by 20% of Jensen et al's (2007) study, but no further details were given; these findings bring some clarification to the issues which are faced by CH sufferers and expand on their study.

## **Lack of understanding: Society**

People hear the word 'headache' and cannot comprehend that a CH is in a league of its own:

*'I have had that once... I took an anadin.'* Int2: 122 [comment from colleague]

*'...try not working so hard, don't stress yourself out at work so much, it might help.'*

Int4:243-244 [comment from family member]

Lack of understanding was a common occurrence which existed outside of the participant's immediate circle of close family and friends. Unhelpful comments were received by 3 of the participants, which implied people undermined the devastating effects that CH had on their life. No specific studies could be found to demonstrate the extent of this, possibly through the small number of qualitative studies on CH. However, Lonardi (2007) reports that stigmatisation can be problematic for serious headache sufferers, as people view headaches as a minor complaint and cannot ascertain the impact they can have on a sufferer's life. This is expanded upon by Park et al (2010, cited in Robert, 2010) whose study demonstrated that migraine was significantly misunderstood and under-rated when compared to other neurological conditions.

### **Friendships: Negatives and positives**

Living with chronic pain can be a testing time for friendships; however, whereas some friendships are lost, others can be strengthened:

*'...I've lost a lot of friends through it... I know that my friends who have stuck by me are my friends.'* Int2:129-131

*'...lots of times I'll have to cancel and in the end they don't ask you... but proper friends, we'll go to their house and they just say if you feel anything coming on, just go in the garden or upstairs.'* Int3:273-276

CH restricted the participant's ability to participate in social activities and reliably keep appointments. As a result, friendships had been affected and although some friendships were lost, true friendships were strengthened. Again, no precise literature relating to CH and friendships could be found. Nonetheless, the findings from this part of the study relate to Goffman (1990); because, although 3 participants had firsthand experience of 'normals' who ended up distancing themselves, they were also very fortunate to have 'wise' people in their lives, and these are the most important people who tend to remain loyal and supportive.

### **Spouse**

It was reported by 3 of the participants that their partners' lives had also been affected:

*'Whenever I'm having a cluster headache bout, if it's a bad one it affects his health as well.'* Int1:339-340

*'My wife has stopped attending her art classes in order to avoid leaving me at home on oxygen alone – if I were to fall asleep I would suffocate.'* Int4:348-349

The 3 married participants were fortunate to have partners who were supportive and also had a great understanding of their condition; however, CH did have quite an

impact on their lives too. When CH struck throughout the night, which was a frequent occurrence, 2 of the spouses also had to also forego sleep, as the oxygen masks used by CH sufferers are non-rebreathable; hence, the user cannot be alone whilst using it in case they fall asleep and suffocate. For this reason, 1 participant reported that his wife also had to give up her hobby. Another participant reported her husband's health was negatively affected by eczema flare-ups and stomach-upsets, when she was having a particularly troublesome bout. Over 50% of Jurgen et al's (2010) sample believed CH impacted on their relationships, but no further information was given. This study can expand on this by adding that sleep, health and hobbies of partners who live with a sufferer can all be disturbed. As 1 family member who lived with a migraine sufferer asserted in Ruiz de Velasco's (2003) study; a headache is not just contained within the individual, when it strikes the sufferer, it strikes the family too.

## **Conclusion**

The aim of this study was to report how CH impacted on the sufferer's emotional wellbeing and day-to-day functioning. To answer this question, it would be easier to explain which parts of their lives were *not* affected, as the disorder had impacted on their character, employment, social life, home life and sleeping patterns. Furthermore, although a theme could not be made from the following, due to no quotes available to support it, 1 participant also reported the negative impact CH had on his sex life. When you add all of these factors together, it would be difficult to report any part of their life that this invisible disease had not invaded. Despite these difficulties and challenges which were common to all the participants, they all had a remarkable strength of character and did not display any hint of self-pity. As a result, these interviews were not only fascinating and informative, but also a personally enriching experience.

## **Limitations**

The researcher could be classed as being a limitation to this study, due to living with the disorder. However, the following steps were taken to ensure the interviews were objective: the researcher's supervisor was present throughout each interview to ensure that no biased questions were asked which could have influenced the participant's replies. Also, the pre-set open-ended questions which arose through reading articles on headache disorders were asked in a neutral, non-leading manner. However, although caution was exercised when reporting the results/discussion section to avoid any forms of bias, it is still possible this section would have been reported in a different manner by a non-sufferer. Also, due to limited time and resources, the researcher cannot give surety that data saturation was reached.

The small sample size could be classed as a limitation, because the results cannot necessarily be classed as being applicable to the wider CH population. However, many of the subthemes corresponded with, or expanded on larger scale CH studies, plus some findings were reported which had not been covered in other research articles on CH.

## **Suggestions for future research**

Jurgen et al (2010) asserts that there is a shortage of studies which explicitly explore how CH can affect family life. It is possible that having a family member or housemate participating in future interviews may allow for explorations into areas which the sufferer alone may not be fully aware of. Another consideration arose through reading research by Lonardi (2007), who highlighted that other neurological disorders such as MS are not down-played, whereas serious headache disorders are. Maybe some future research studies could compare quality-of-life data collected from CH sufferers to that of other neurological disorders which *are* taken seriously? If the results found that quality-of-life issues were equally affected, and this was subject to large sample sizes from quantitative methods, then examined in more depth through qualitative methods, perhaps the seriousness of CH would become more understood and less underrated.



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