

**Experiences of Living with and Managing Episodic Tension-Type
Headache in Adults: An Interpretative Phenomenological Analysis**

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List of abbreviations

BASH	British Association for the Study of Headache
CAM	Complementary and alternate medicine
CHD	Chronic headache disorder
CTTH	Chronic tension type headache
ETTH	Episodic tension type headache
GP	General practitioner
ICHD beta-3	The International Classification of Headache Disorders
IHS	Headache Classification Subcommittee of the International Headache Society
IPA	Interpretative phenomenological analysis
NICE	National Institute for Clinical Excellence
NSAIDs	Nonsteroidal anti-inflammatory drugs
OTC	Over the counter medication
SR	Systematic review

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I dedicate this work to my grandfather –Kashmira Singh Rana (deceased).

Foreword

I began my Professional Doctorate in Health Psychology (stage 2 training) at the University of the West of England in January 2012. To date, I have successfully completed four out of the five competencies: behaviour change interventions, consultancy, professional skills and teaching and training competencies.

The research component to this programme is the final competency. This is divided into two parts. Part 1 involved carrying out a systematic review (SR) (see Annex 1 for the full SR) and part 2 a thesis. I have successfully completed the systematic review (part 1). The pass mark has been verified by the University of the West of England's examination board. The review is titled 'Are Cognitive/Behavioural Therapies Effective in Reducing Head Pain and Psychological Distress and Increasing Coping in Adults Diagnosed with Migraine/Tension-type Headache? A Systematic Review of Randomised Controlled Trials and Non-Randomised Studies' appears in full in Annex One and contributed to the literature review in Chapter Two, underpinning the specific research in this thesis.

Throughout the professional doctorate I have continued to work as an academic and with service users in practice. During this time, my positivist orientation to research has begun to change. I found that I wanted to get to the crux of the experiences of individuals with episodic tension-type headache (ETTH). This led me to conceptualise and design this qualitative study (please see also, Reflexivity Chapter in Appendix A). It is this research that forms the focus of my thesis, submitted as evidence for the Research competence as part of the award of Professional Doctorate in Health Psychology.

Abstract

Background: Research relating to the experience of headaches has, in the main, focused on the management of tension-type headache (TTH)/migraine, with limited research on episodic TTH. The current study aimed to explore the experiences of living with and managing ETTH through the use of interpretative phenomenological analysis (IPA) (Smith, Flowers & Larkin, 2009). **Methods:** Purposive sampling was used to recruit 9 volunteers (aged 18 years and over) from a community sample in the UK, self-selecting as having ETTH. Semi-structured individual interviews were audio recorded and transcribed verbatim. **Findings:** Three superordinate themes emerged: (1) the essential and versatile use of coping strategies; (2) the intricate relationship between functioning and (dys)functioning and (3) a love-hate relationship with health professionals and medication. The intention to use adaptive coping strategies and self-care health behaviours was compromised by demands of functioning and stressors (Lazarus & Folkman, 1984). The sharing of similar experiences of effective management strategies was beneficial and individuals were not fixed but versatile in their management of ETTH. **Discussion:** The results were used to underpin the following recommendations: a) further explore the utility of CBT and third wave interventions to promote awareness of stress and acceptance of ETTH in those affected; b) increase patient awareness of the barriers to effective self-care health behaviours; c) create face-to-face/on-line groups to empower individuals to self-manage ETTH effectively. **Conclusion:** This study showed that despite ETTH being classed as a ‘mild headache’ (Headache Classification of the International Headache Society [IHS], 2013), this condition is fraught with difficulties. Further research into ETTH is warranted to support and empower individuals in managing and living with ETTH.

Chapter One

Introduction

Introduction

This study explores the experience of living with and managing episodic tension-type headache (ETTH). Frith (2016) describes headache as a common occurrence, affecting more than 10 million people in the UK, and Russell (2005) suggests that tension-type headache, in its episodic subtype, is the most common headache, affecting up to 82% of people in the UK. As ETTH impacts more of the population than any other headache type (Rasmussen, Jensen, Schroll & Olesen, 1991), addressing ETTH in the research literature is of the utmost importance.

McCaffery (1968) defines pain as “whatever the experiencing person says it is” (p. 95). This is the approach I will take throughout this study. In this sense, the lived experience of managing ETTH is what participants in this study say it is, as lived by them.

I have chosen to write this study in the first-person for the following reasons: a) I can show my engagement in the study process and invite the reader to also feel engaged, b) my personal voice and reflexivity is presented throughout the study in my writing, c) my own views are reflected, and d) the narrative of each participant is given justice in relation to how they constructed and gave meaning to their experiences of living with and managing ETTH.

The Appeal of Interpretative Phenomenological Analysis (IPA)

I wanted to explore ETTH in detail as it is experienced, understood, and interpreted by each individual, and this drew me to IPA. Phenomenology is the philosophical approach to the study of experience, which is the first major influence upon interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009). At the same time, I wanted to explore how individuals interpreted and understood their experiences of ETTH and how I could then bring health psychology understandings to bear on their experiences; hence, I considered IPA, an approach developed by Smith et

al. (2009) and guided by three major influences. The first of IPA's influences is phenomenology, which is the study of individuals' experience. The second influence is the use of double hermeneutics in the interpretation of experience: in this sense, the individual first interprets his or her own experience during an interview, and then the researcher interprets the individual's interpretation of the experience during the data analysis (Smith et al., 2009). The final principle of IPA is the commitment to an idiographic approach, concerned with thorough and in-depth analysis as well as a commitment to each individual case (Smith et al., 2009). Using this method has allowed me to convey how individuals live with and manage ETTH, derived from the experts (the individuals) who experience the phenomena (Smith et al., 2009).

My Positionality in This Thesis

Positionality refers to the researcher's philosophical perspective, where several core assumptions concerning two specific dimensions are made: the nature of society and the nature of science. My positionality is from a post-modernist view of society, and in this thesis, a subjective approach will be taken involving my core assumptions concerning ontology (reality), epistemology (knowledge), human nature (pre-determined or not), and methodology (Burrell & Morgan, 2005). I also position myself as developing an understanding of ETTH which is individual and subjective to each individual participant. In addition, I accept that I will never arrive at one objective truth regarding the experience of ETTH, as this changes between individuals and is subject to new experiences and different interpretations (Smith et al., 2009).

Prominent researchers who have explored ETTH in the past (e.g., Rollnik, Karst, Fink & Dengler, 2001; Slettbakk, Nilsen & Malterud, 2006) have failed to discuss how they themselves defined and understood ETTH. With this in mind, I position myself with Morris (1991), who describes pain as "not being the sole creation of anatomy and physiology, but it emerges only at the intersection of bodies, minds, and cultures" (p. 1),

and with Rutberg and Öhrling (2012), who entitled their research paper “Migraine - more than a headache” (p. 329).

Chapter Two
Literature Review

Literature Review

Background

The present thesis focuses on the experience of living with and managing episodic tension-type headache (ETTH). While ETTH is characterised as a less intense and frequent headache when compared with chronic TTH (CTTH) and migraine (Headache Classification of the International Headache Society [IHS], 2013), it can be just as disabling if not managed well (Schwartz, Stewart, Simon & Lipton, 1998; Slettbakk et al., 2006). ETTH is the most prevalent headache disorder, impacting 82% of individuals in the UK (Russell, 2005), but it has been relegated to the background by most researchers and clinicians (Bendtsen, Fumal & Schoenen, 2010; Folchini & Kowacs, 2015; Robbins & Lipton, 2010; Yu & Han, 2015) while research on migraines has flourished (Pietrobon & Moskowitz, 2013). The two overarching reasons for this are: a) patients with episodic forms of headache tend not to be very visible in clinical settings, as they are rarely referred for specialist care owing to less frequent and less severe nature of their headaches compared with other headache groupings (Bendtsen & Jensen, 2006; Frith, 2016; Robbins & Lipton, 2010; Waldie, Buckley, Bull & Poulton, 2015), and b) the pathophysiology of TTH is in its infancy (Jensen, 1999; Waldie et al., 2015), making it difficult to define subtypes on the basis of objective symptoms (Slettbakk et al., 2006). Consequently, TTH is referred to as the ‘ugly duckling’ of headache disorders (Folchini & Kowacs, 2015). Due to this lack of previous research, I will draw on both migraine and TTH studies to inform the rationale of this study. Firstly, I will distinguish classifications and the prevalence of TTH so that ETTH can be placed in the proper context.

Terminology, prevalence, classification, and diagnosis of migraine/TTH.

The IHS (2013) identifies four sub-classifications of TTH: infrequent ETTH, frequent ETTH, CTTH, and probable TTH. In this thesis, I will distinguish between ETTH

(frequent: 10 episodes, 1-14 days per month/average for >3 months) and CTTH (>15 days per month for >3 months) (IHS, 2013). Differentiating CTTH/ETTH allows for variability in psychophysiology and pharmacological management (Frith, 2016; IHS, 2013; Magazi & Manyane, 2015) and an understanding of the varying impact on quality of life and disability (Bendsten et al., 2010; IHS, 2013; Magazi & Manyane, 2015). Despite this, an overwhelming amount of research explores TTH without its sub-classifications (e.g., Cathcart & Pritchard, 2008; Eskin, Akyol, Çelik & Gültekin, 2013; Özdemir, Aykan & Güzel-Özdemir, 2014). I cite TTH research below in which researchers have not distinguished between CTTH/ETTH, bringing into question the incidence of migraine/TTH and their sub-classifications and the characteristics of those affected by the sub-types.

Migraine/TTH make up 92% of headaches (Ahmed, 2012; Göbel, Buschmann, Heinze & Henize-Kuhn, 2000), with a higher global prevalence rate for TTH (m: 14% to 69%; f: 26% to 86%) (Russell, Rasmussen, Thorvaldsen & Olesen, 1995) when compared with migraine (m: 6% to 12%; f: 15% to 25%) (Henry et al., 1992).

Population based studies conclude that the most common age of onset for TTH is 25-30 years (Rasmussen, 1995), peaking at 30 to 39 years (Bendtsen et al., 2010). However, a minority of people with TTH have CTTH ranging from 0.6% to 3.3% (Sahler, 2012) whereas the majority, ranging from 10.8% (Yu & Hans, 2012) to 80% (Rasmussen et al., 1991) have ETTH. Nevertheless, this receives little attention in research and clinical practice due to its status as a mild headache (Jensen, 1999; Lenaerts, 2006; Slettbakk et al., 2006), which raises the question about the specific characteristics of ETTH that distinguish it from CTTH and migraine.

The International Classification of Headache Disorders (ICHD-3 beta) (IHS, 2013) is a diagnostic tool for headache disorders (Osipova, 2016). Migraine is characterised by a minimum of five attacks of moderate or severe pain intensity, lasting

between four and seventy-two hours (when untreated in adults), with unilateral location and a pulsating quality aggravated by physical activity, where nausea/vomiting or photophobia and phonophobia could be present (IHS, 2013). TTH is typically characterised as a mild to moderate pain intensity lasting from thirty minutes to seven days, with bilateral location of a pressing/tightening (non-pulsating) quality which does not meet with the characteristics for migraine (IHS, 2013). The criteria further classify TTH based on frequency; I look at ETTH (frequent: 10 episodes, 1-14 days per month/average for >3 months) and refer to CTTH (>15 days per month for >3 months) (IHS, 2013). This diagnostic tool has limited value in describing what it means to experience headache (Rutberg, Öhrling & Kostenius, 2013), focusing on the symptoms rather than the person (British Association for the Study of Headache, [BASH], 2010). Furthermore, TTH is based on what it is not (absence of migraine symptoms) rather than what the symptoms are (Kundu & Ahmad, 2004; Waldie et al., 2015). This brings into sharp focus how the ICHD-3 beta (IHS, 2013) is used in the diagnosis of migraine/TTH by health professionals.

To accurately diagnose migraine/TTH, issues other than primary headache are ruled out (Loder & Rizzoli, 2008), a patient history is taken against a checklist based on the ICHD-3 beta for headache classification (BASH, 2010; IHS, 2013; National Institute for Clinical Excellence, [NICE], 2016), and a 4-week diary is implemented (NICE, 2016; Russell et al., 1992), meaning that experiences are reduced to symptoms identified on a checklist (BASH, 2010; NICE, 2016). Furthermore, diagnosis of TTH is not without its challenges, with only 1.3% attaining the correct diagnosis of TTH (Ertas et al., 2012). In addition, an overlap of symptoms makes it hard to determine the presence of migraine/TTH (BASH, 2010; Kaniecki, 2002; Kaynak, Donmez & Tuzun, 2004; Waldie & Poulton, 2002), meaning mild migraine and ETTH are easily confused (BASH, 2010) and GPs are more likely to diagnose mild migraine (Kaniecki, 2002;

Nadkar, Desai & Itollikar, 2010). This is also partly due to individuals with ETTH being less likely to visit GPs, leading to referral bias (Rasmussen et al., 1991). Therefore, an insight into how individuals interpret, respond, and attribute meaning to their symptoms is needed (Peters, Abu-Saad, Vydellingum & Murphy, 2002; Rutberg et al, 2013; Sarantakos, 1998), part of which involves understanding the causes of migraine/TTH which are not identified on the ICHD-3 (IHS, 2013) checklist recommended by NICE (2016) and BASH (2010).

Predisposition and propensity to migraine/TTH. There is strong evidence to suggest that migraine symptoms arise from neurological (Gasparini, Sutherland & Griffiths, 2013; Schoenen & Sándor, 2004) and vascular dysfunctions (Eadie, 2005; Rapoport & Edmeads, 2000). In comparison, although the neurological mechanisms of TTH are unknown, several studies have demonstrated a relationship between neck or head injury and headache (Côté, Cassidy & Carroll, 2000; Loder & Rizzoli, 2008; Scher, Midgette & Lipton, 2008), resulting in bilateral pain (IHS, 2013) stemming from the neck (Sjaastad, 2011). Predisposing factors are not only restricted to neurobiological and genetic explanations; personality traits have also been implicated as having a part to play (Eskin et al., 2013).

Cross-sectional studies have determined that dysfunctional personality traits such as neuroticism and stress, anxiety, and depression are significantly higher in individuals with TTH/migraine when compared with healthy controls (Cathcart & Pritchard, 2008; Eskin et al., 2013; Huber & Henrich, 2003; Özdemir et al., 2014), CTTH (Aaseth et al., 2011), and ETTH (Cao, Zhang, Wang, Wang & Wang, 2002). Although Rollnik, et al. (2001) found subtle differences and concluded that individuals with CTTH were more depressed than those with ETTH, they failed to discuss how they defined and distinguished between ETTH and CTTH. While these studies provide evidence for an association between TTH/migraine and personality dysfunctions, they

do not consider how these traits impact on an individual's thinking, functioning, and behaviour, all which embodies personality (Ganellen, 2013). Furthermore, triggers have been found to precipitate the onset of migraine/TTH in predisposed individuals (Iliopoulos et al., 2015), where the predisposition of an individual partly sheds light on the onset of migraine/TTH.

Cross-sectional (Constantinides et al., 2015; Iliopoulos et al., 2015; Wang et al., 2013), population (Rasmussen, Jensen, Schroll & Olesen, 1992; Ulrich, Russell, Jensen & Olesen, 1996) and mixed methods studies (Wöber, Holzhammer, Zeithofer, Wessely & Wöber-Bingöl, 2006) have indicated that headache triggers precipitate migraine/TTH in predisposed individuals. For example, Wöber et al. (2006) found that weather, stress, menstruation, hunger, and changes in sleeping patterns were common triggers experienced by individuals with TTH/migraine. However, the researchers did not identify how each of these triggers related to each headache type and how the triggers were managed in order to reduce the headaches. When comparing migraine/TTH triggers, there are differences. Alcohol, diet, and insomnia are cited as triggers in migraine (Constantinides et al., 2015), whereas stress, sleep, coffee, and physical exercise are triggers for TTH (Constantinides et al., 2015; Rasmussen et al., 1992). While one study investigated ETTH and triggers, finding that an imbalance of coffee, sleep, exercise, and hydration were common triggers for women (Slettbakk et al., 2006), it did not touch upon how these women experienced and managed these triggers through their first-hand experience (Smith et al., 2009; van Manen, 2007).

While the ICHD-3 beta diagnostic criteria (IHS, 2013) distinguishes symptoms of headaches, and epidemiological and population based studies have determined the prevalence and causes of the onset of migraine/TTH, little is known about ETTH. Furthermore, using patients' symptom experiences as knowledge resources (Malterud, 2000) to help understand how individuals experience and are impacted by

migraine/TTH (Malterud, 2000) may be of aid in better understanding and interpreting their situations (Hollnagel & Malterud, 1995).

Experiencing Migraine/TTH

In this study, living with migraine/TTH will be appraised from the biopsychosocial perspective (Engel, 1977), which allows for the symptoms of headache to be understood from a holistic viewpoint as experienced by the individual in relation to how they function physically, psychologically, and socially.

How do individuals experience the impact of migraine/TTH on their physical, psychological, and social functioning? Population-based studies show 57% to 85% of individuals with migraine (Lipton, Stewart, Reed & Diamond, 2001; Magnusson & Becker, 2003; Plesh, Adams & Gansky, 2012; Stewart, Schechter & Lipton, 1994), and 8.12% with TTH rate their pain as severe (Hilton, Roberta, Simone, Carlo & José, 2004). When looking at ETTH alone, up to 11% of ETTH individuals assign the label severe (Silva, Garbelini, Texeira, Bordini & Speciali, 2004). While studies show migraine to be associated with more individuals affected by severe pain than those with TTH, pain is confined to pre-determined categories (Conrad & Barker, 2010) that do not consider how the individual experiences the impact of pain.

Qualitative studies looking at migraine have shed light on how individuals experience the impact of pain. For example, a large number of qualitative studies found that pain was associated with emotional and psychological aspects of the self (Belam et al., 2005; Helvig & Minick, 2013; Moloney, Sritckland, DeRossett, Melby & Dietrich, 2006; Peters, Abu-Saad, Vydelingum & Murphy, 2005; Ramsey, 2012; Rutberg & Öhrling, 2012). Both Ramsey (2012) and Rutberg and Öhrling (2012) carried out hermeneutic phenomenology studies looking at women with migraines. In the former, the women reported how they battled with pain, described as torture, while getting on with their lives, whereas in the latter, women with migraine described their pain as hard

to endure and incapacitating, which was associated with vulnerability. However, it is important to note that these studies focused only on women with migraine. In addition, Peters et al. (2005) explored chronic headache disorder (CHD) and migraine (including 3 individuals with TTH), with participants describing their pain as disabling. Although the researchers discussed these findings collectively, they left out the question of how the individuals with TTH experienced their pain. Also, the researchers did not define headache types, leaving me to question if individuals with ETTH were included in this study.

Furthermore, these studies depict extreme static descriptions of pain, thus failing to demonstrate how pain can change over time. This also raises the additional question of how individuals with ETTH who experience less intense and frequent pain (BASH, 2010) describe their experiences of the impact of pain. Pain alone is not the only symptom of migraine/TTH, and additional symptoms which characterise migraine/TTH are also worthy of consideration (BASH, 2010; IHS, 2013).

Studies have shown migraine to be associated with accompanying symptoms of vomiting, nausea, photophobia, and phonophobia (Domingues, Aquino, Santos, Pirajada Silva & Kuster, 2006; Martin et al., 2000), with qualitative studies discovering how feeling sick/nauseous, visual impairment, and the slurring of speech are central to the experience of an individual's migraine (Belam et al., 2005; Helvig & Minick, 2013; Rutberg & Öhrling, 2012). For example, it was found that, for women, feeling nauseous/sick was described as the worse part of a migraine (Rutberg & Öhrling, 2012) whereas in the research of Belam et al. (2005), the individuals suffering from migraine selected the feeling of pain as the worst.

Visual disturbance was associated with a feeling of incapacitation (Rutberg & Öhrling, 2012) and disorientation (Moloney et al., 2006). Again, these studies provide static descriptions and do not shed light on how individuals feel when not experiencing

these symptoms. This raises the question about the symptoms experienced by individuals with TTH as, currently, TTH is classed as a featureless headache by the IHS (2013) (Waldie, 2015). Furthermore, the cycle of pain and emotion has been found to be interrelated, where psychological factors are central to the experience of pain (Gatchel, Peng, Peters, Fuchs & Turk, 2007), a relationship which is not indicated on the ICHD-3 beta (IHS, 2013) or the checklists used by GPs to diagnose headache (BASH, 2010).

Cross-sectional studies have evidenced the association between TTH and anxiety and depression (Adler & Adler, 1987; Baskin, Lipchik & Smitherman, 2006; Hatch et al., 1991). The results indicate that anxiety is common in ETTH but is lower than episodic migraine (migraine: 15%; ETTH: 4.7%) (Lampl et al., 2016). However, it is difficult to ascertain from this how TTH/migraine has an adverse impact on psychological functioning.

Qualitative studies have evidenced how migraine (Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006) and TTH (Leiper, Elliot & Hannaford, 2006) have an adverse impact on psychological functioning. For example, in Helvig and Minick (2013) adolescents reported how migraine made them feel guilty, helpless, distressed, and worried, and they described how having too much on one's mind resulted in migraine. Rutberg and Öhrling (2012) alluded to women with migraine feeling helpless as they described how they lived a life full of uncertainty. Further guilt was described when migraine took them away from daily activities. However, the adverse effects on psychological functioning are not only restricted to episodes of the migraines themselves. For example, Moloney et al. (2006) and Wacogne, Lacoste, Guillibert, Hugues and Le Jeunne (2003) found that, in-between attacks, women with migraine described feelings of fear, worry, and anxiety associated with an anticipation of the next attack. For others, the impact of migraine resulted in descriptions of depression and

suicidal thoughts in men and women with migraine (Belam et al., 2005). The impact of TTH/migraine on psychological functioning has been further evidenced.

Leiper et al. (2006) reported a state of constant worry about the underlying causes of headache in individuals with migraine/TTH, a situation also found by Moloney et al. (2006) in women with migraine. However, Leiper et al. (2006) did not discuss how worry differentially impacted migraine and TTH. This also raises questions about how individuals with ETTH who have less frequent headaches are psychologically impacted. The third aspect in understanding migraine/TTH from a holistic perspective is how individuals experience symptoms when functioning socially, which is the latter dimension in Engel's (1977) biopsychosocial model.

Cross-sectional studies show that the UK loses 25 million days from work or school because of migraine (Lipton, Stewart, Diamond, Diamond & Reed, 2001; Steiner et al., 2003b). This also brings into question if and how individuals are impacted by migraine/TTH when they go to work. Qualitative research suggests that when individuals experience migraine/TTH (Leiper et al., 2006) or migraine (Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhrling, 2012), they push through and work so that they are not doubted or seen as lazy, wanting to avoid responsibilities, or inadequate. In Moloney et al.'s (2006) study, women with migraines described how they felt doubted due to living with an invisible disorder, while in Rutberg and Öhrling (2012), women with migraines associated this with co-workers assuming headaches were the same as migraines. The psychological impact of living with an invisible disorder has also been echoed by individuals living with Chronic Fatigue Syndrome/Myalgia Encephalomyelitis (CFS/ME) (Clarke & James, 2003; Whitehead, 2006).

At the same time, many of the women did not want to admit having migraines as it was felt that this would lead to feelings of shame about not being able to control their conditions (Moloney et al., 2006; Rutberg & Öhrling, 2012), thus leading some women

to play down the seriousness of migraine (Moloney et al., 2006). Qualitative studies have shown how women with migraines viewed this as the price to pay for sustaining a career, with migraine/TTH instead having an impact on family life. This sentiment was also voiced by family members of those with migraines, who described how doing a good job meant time away from the family yet having to rest or being in pain at home meant that the family members paid the price (Ruiz de Velasco, González, Etxeberria & Garcia-Monco, 2003). In comparison to migraine, a smaller number of individuals with ETTH - 8.3% - lose workdays, but up to 43.6% experience reduced work effectiveness (Schwartz et al., 1998). It is therefore important to understand how TTH/migraine affects an individual's work life, and if this also impacts on their quality of life outside of work.

Studies have indicated that headaches damage the family and social life of the individual as well as those surrounding them (Gowri, Eswari, Chandrasekar & Chandra, 2014), with lower quality of life scores reported in individuals with migraine when compared with healthy populations (Lipton, Hamelsky, Kolodner, Steiner & Stewart, 2000; Magnusson & Becker, 2003; Terwindt et al., 2000). In addition, psychosocial quality of life is lower in individuals with TTH when compared with headache free individuals (Lyngberg, Rasmussen, Jørgensen & Jensen, 2005), with 18% of TTH individuals discontinuing their normal activities (Degges-White, Myers, Adelman & Pastoor, 2003).

Qualitative studies have also shown that family life/activities are disrupted due to migraine as individuals with TTH/migraine (Leiper et al., 2006; Ruiz de Velasco et al., 2003) need to be alone to rest (Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006; Ramsey, 2012; Rutberg et al., 2013). However, while adolescents with migraine (Helvig & Minick, 2013) and TTH/migraine (Leiper et al., 2006) found disengaging from social activities and family important for therapeutic rest (Ramsey,

2012), Moloney et al. (2006) concluded that women with migraine considered surrendering themselves to bedrest as a luxury they could not afford due to their work commitments and the need to care for children. In this sense, guilt was increased in individuals with migraines (Belam et al., 2005) when children's needs were put on hold and when going to work meant weekend family activities were disrupted (Moloney et al., 2006; Ramsey, 2012). The unpredictability of headaches was reported to impact on family life in adults with TTH/migraine in instances where they missed out on something they were looking forward to or had their enjoyment of an event spoiled due to feeling miserable or guilty (Leiper et al., 2006). A few studies focused on individuals getting on with life, irrespective of headache, as they did not want migraine/TTH to govern them (Leiper et al., 2006; Rutberg & Öhring, 2012). While cross-sectional studies have indicated that family and social activities are affected due to ETTH (Schwartz et al., 1998), there has been no insight offered into how individuals with ETTH experience the impact on social functioning.

While the aforementioned studies have evidenced how individuals are impacted physically, psychologically, and socially, a key determinant of this impact is how the individual adapts in relation to coping with and managing such impacts (Litt & Tennen, 2015). The remainder of this review will look at how individuals manage and cope with migraine/TTH.

Managing Migraine/TTH

Self-management is an ambiguous term often used interchangeably with the terms self-care and self-help (Curtin, Mapes, Schatell & Burrows-Hudson, 2005; Phillips, 2012). Johnston, Rogerson, Macijauskiene, Blaževičienė and Cholewka (2014) define self-care as “the care of oneself without medical, professional, or other assistance or oversight” (p. 4), and self-help has also been described as “the use of one's own efforts and resources to achieve something without relying on others” (Maw, 2015, p.

127). An inter-related concept that is also used when discussing self-management is coping (Peters, Abu-Saad, Vydelingum, Dowson & Murphy, 2004). Literature focusing on pain verify coping strategies as mediators of pain (DasMahapatra, Chiauzzi, Pujol, Los & Trudeau, 2015; Esteven, Ramírez-Masestre & López-Marínez, 2007). Coping has been defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Folkman, Lazarus, Gruen & DeLongis, 1986, p. 572). The reappraisal process influences the subsequent coping behaviour and response, which has been distinguished between two major functions; problem-focused coping and emotion-focused coping (Lazarus & Folkman, 1984). Peters et al. (2004) did not consider coping as part of the ‘strategies’ for managing headache. I have therefore considered coping in the discussion below, which appraises research concerned with self-management, self-care, and self-help.

Through employing a grounded theory methodology, Peters et al. (2004) found that medication, healthcare use, alternative therapies, social support, and self-help/lifestyle strategies were used to manage headaches in 13 patients with migraine/chronic headache disorder (CHD), including 3 individuals with TTH. However, as the researchers predominantly focused on medication and the use of healthcare, these strategies only constituted a limited part of managing ETTH (Slettbakk et al., 2006). Furthermore, the researchers discussed migraine/TTH collectively, leaving me curious as to which of these strategies are used to manage TTH. Peters et al. (2004) use the term ‘management’, which in health literature is referred to as self-management and has been defined by Long and Brettle (2015) as “the active engagement of patients in their treatment and collaboration with healthcare practitioners in the management of their condition” (p. 34). Next, I will consider how individuals manage TTH/migraine with medication.

Medication and healthcare. NICE (2016) guidelines recommend a three-step combined medication approach for the treatment of acute and severe migraine, involving over-the-counter (OTC) nonsteroidal anti-inflammatory drugs (NSAIDs), prescribed tri-cyclic antidepressants (Sekhar, Sasidharan, Joseph & Kumar, 2012) and preventative medication (antidepressants and amitriptyline) (Sekhar et al., 2012). While the effectiveness of these treatments has been widely reported in clinical trials (Silberstein et al., 2012; Tfelt-Hansen et al., 2012), these studies do not provide any insight into how individuals use medication to manage TTH/migraine.

An overwhelming number of qualitative studies have shown that medication has more extensive effects than just reducing headache when managing migraine (Meyer, 2002; Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhring, 2012) and migraine/CHD (Peters et al., 2004; Peters et al., 2005). Rutberg and Öhring (2012) found that medication allowed women with migraines a greater level of functioning in their everyday lives, a fact that was associated with having control over the unpredictability of migraine attacks. The association between medication and control has been echoed by other studies. Moloney et al. (2006) determined that medication acted as a safety net, providing the women with a sense of control over migraines. This led to behaviour such as always keeping an arsenal of medication with them so that they would not be caught unawares by migraine, a finding common in other studies (e.g., Meyer, 2002). At the same time, the women reported stories of desperation and fear when medication was not close by (Moloney et al., 2006). These studies imply a simplistic relationship between control and how individuals feel with or without medication at hand. While some of these studies have shed light on the distress individuals experience when without medication, they do not discuss the psychological issues that may relate to a dependency on medication.

Jonsson et al. (2013) discuss how medication overuse headache (MOH) occurs in headache-prone individuals who are psychologically and physically dependent on over-the-counter medication (OCM), particularly when this is their prevailing approach for coping with headaches. Most headaches in patients with ETTH are mild to moderate, and patients can often self-manage using simple analgesic OCMs, such as aspirin (Steiner, Lange & Voelker, 2003a), acetaminophen (Prior, Cooper, May & Bowen, 2002; Steiner et al., 2003a) and non-steroidal anti-inflammatory drugs (NSAIDs) (Ashina & Ashina, 2003). However, the efficacy of analgesics decreases with the increased frequency of headaches, and there is a risk of MOH due to a reliance on OCMs (Jensen & Bendsten, 2008). Accordingly, the question arises whether the relationship between medication and managing ETTH is more complicated than with the case of migraine (Moloney et al., 2006; Rutberg & Öhrling, 2012) due to the reliance on OCMs.

A common finding emerging from qualitative studies is that, in terms of managing headache among females with migraine, the decision to take medication is not made lightly (Meyer et al., 2002; Moloney et al., 2006; Rutberg & Öhrling, 2012); this is the case for managing migraine (Rutberg et al., 2013), migraine/CHD (Peters et al., 2005), and migraine/TTH (Leiper et al., 2006). These studies allude to a psychological struggle between the necessity of having to take medication and experiencing or being concerned about side-effects, which leads to continual experimentation in terms of medication use (Meyer, 2002; Moloney et al., 2006; Rutberg & Öhrling, 2012). Moloney et al. (2006) found that medication such as beta-blockers was discarded by some women who experienced severe side-effects, for example, dizziness and not being aware of the environment around them. These studies also provide information on individuals who decide not to take medication and how they experience headache. For example, Wieser, Walliser, Womastek and Kress (2012)

explored the way in which some individuals use endurance coping, where they manage headache without medication. This type of coping is dysfunctional as episodic forms of headache can develop into chronic pain. Indeed, 16% of individuals with ETTH can develop chronic TTH (Chowdhury, 2012). In turn, it would be interesting to gain further insight into how individuals with ETTH use medication to cope with headaches and whether endurance coping or over-dependency on medication features as part of their experiences of managing headaches.

As previously mentioned, the decision to take medication for migraine/CHD is not an easy one (Peters et al., 2004; Rutberg & Öhrling, 2012). For example, Rutberg and Öhrling (2012) described how women weighed up the necessity of taking medication, depending on their day ahead and whether they could cope without the medication. Often, medication was needed for individuals to be able to function, despite having concerns about their side-effects, which for some individuals with migraine/CHD meant giving in to the migraine (Peters et al., 2005; Rutberg & Öhrling, 2012). While these studies touched upon how pivotal individuals are in the decision of whether to take medication and experience the associated side-effects, this raises the question of whether this struggle is also faced by individuals with ETTH, who rely on OTCMs and where such adverse side-effects will not be experienced (Frith, 2016). Furthermore, these studies fail to highlight whether medication is being abused, overused, or misused, which, according to Jonsson et al. (2013), can occur amongst individuals who are prone to headaches or may not be in control of medication-taking, a situation that increases with the use of OTCMs. Studies have also explored how visiting a healthcare provider can mediate the relationship between the individual with TTH/migraine and medication taking.

Qualitative studies on individuals with migraine/CHD (Peters et al., 2004; Peters et al., 2005), migraine (Rutberg et al., 2013), women with migraine (Moloney et al.,

2006; Rutberg & Öhring, 2012), and TTH/migraine have found GPs, neurologists, and nurses to be part of how individuals manage and cope with headaches. However, studies have shown that the likelihood of visiting a healthcare provider is mediated by the coping style of the individual (Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006; Peters et al., 2004). For example, Peters et al. (2005) found that individuals with migraine/CHD who used an active coping style consulted their GPs, compared to those with a passive coping style who were non-consulters. This is supported by Belam et al. (2005), who found that individuals approached migraine by either taking a fatalistic approach (i.e., why bother?) or engaged in health-seeking behaviour where they were proactive, which involved seeing a GP.

Indeed, it has been suggested that patients with headaches use more maladaptive coping strategies (Wittrock & Myers, 1998), with coping patterns involving strategies of avoidance (Rollnik et al., 2001; Wittrock & Myers, 1998), which can lead to distress (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001). This finding concurs with studies focusing on individuals with migraine/TTH (Leiper et al., 2006) and women with migraines (Moloney et al., 2006). The categorisation of individuals as having consulting and non-consulting styles, or health-seeking and non-health seeking behaviours when managing headache, led me to question the polarisation of either seeing or not seeing a GP and the continuity between these two approaches. These studies do not take into account individuals who may have changed their approaches as a way of coping with headaches.

Research suggests that individuals who visit their GP to manage headache have mixed experiences. For example, through semi-structured interviews with 17 patients experiencing migraines and TTH, Leiper et al. (2006) revealed that a number of patients reported how visiting a GP when first experiencing symptoms of migraine/TTH was important in reducing their anxiety about possibly having an underlying serious illness.

Furthermore, the researchers found that individuals had mixed views about seeing their GPs, with some being either satisfied when the GP was sympathetic and took the time to listen and uncover underlying issues, or finding visits to their GPs unhelpful as the GP was not interested nor sympathetic, merely prescribing medication to resolve their problem. Rutberg and Öhrling (2012) show how some women with migraine found visiting a GP unhelpful, as they felt the GP doubted their accounts as it was an invisible disorder. On the other hand, Belam et al. (2005) found that individuals with a longer history of migraine understood how they were the experts and in a position of strength when consulting their GPs. While these findings provide insight into the positive and negative experiences of visiting a GP, studies have either tended to focus on migraine (Belam et al., 2005; Rutberg & Öhrling, 2012) or have discussed the experiences of visiting the GP collectively for migraine and TTH (i.e. Leiper et al., 2006). Additionally, while migraine is a well-explained medical condition and recognised by GPs (Jensen, 1999), TTH, which presents subjective symptoms and is without objective findings, is not fully understood in medical terms (Slettbakk et al., 2006). It is therefore worth considering how individuals with ETTH experience their interaction with a health practitioner when discussing headaches.

Slettbakk et al. (2006) is the only study in my review that focused on coping in women with ETTH. However, the researchers omitted the experiences of healthcare and medication from their paper, leaving me to question if and how medication and healthcare providers are a significant part of managing headache in individuals with ETTH.

According to epidemiological studies, the use of complementary and alternate medicines (CAM) has been on the rise in the UK, the USA, and Europe (Eisenberg et al., 1998; Posadzki, Watson, Alotaibi & Ernst, 2013; Tindle, Davis, Phillips & Eisenberg, 2005), and in this sense, some individuals also manage their headaches by

visiting health professionals trained in alternative techniques. Although there is no formal definition of CAM, the National Centre for Complementary and Alternative Medicine considers it to be “a group of diverse medical and healthcare systems, practices, and products that are not necessarily considered as part of conventional medicine” (Fontanarosa & Lundberg, 1998, p. 1618). CAM modalities have been divided into physical and psychological therapies that individuals with headache can use (Jensen & Roth, 2005), which I will consider next.

The use of complimentary and alternate therapies (CAM), social support and lifestyle changes. Studies have shown that some individuals using CAM follow the more widely discussed treatments for managing migraine/TTH, including acupuncture, homeopathy, reflexology, and chiropractors. Most individuals also expressed an interest in learning more about less widely used complementary therapies in these studies (Belam et al., 2005; Leiper et al., 2006; Peters et al., 2004; Peters et al., 2005; Rutberg et al., 2013). Users were positive about their experiences as compared to more widely used treatments, these approaches offered a holistic approach and addressed all aspects of their lives (stress, sleep, diet, stretching, exercise, finding the root cause of the headache, etc.) rather than simply their symptoms (Peters et al., 2004). However, for some, uptake was short-lived, as such therapies were either too expensive or did not prove helpful (Leiper et al., 2006). Both Peters et al. (2004) and Leiper et al. (2006) discuss the use of alternative therapies in general for both migraine and TTH. Given this, I am curious about the extent to which alternative therapies have been part of the experience of managing TTH.

According to Jensen and Roth (2005), physical therapy is the most common non-pharmacological treatment for TTH, including the improvement of posture, relaxation, exercise programmes, hot and cold packs, ultrasound, and electrical stimulation. Despite this, access to these interventions has not been highlighted in the

experiences of women with ETTH (Slettbakk et al., 2006). This raises the question about whether access to physical therapies is used in the management of ETTH.

Interestingly, Slettbakk et al. (2006) found that women widely considered physical therapies; which they discussed as being essential to their management of ETTH, these are considered in the lifestyle and self-help section later in this study.

A meta-analysis study conducted by Holroyd, Martin and Nash (2005) concluded that many of the psychological treatments used to treat TTH have received reasonable scientific support for their effectiveness, and these include relaxation training, biofeedback, and cognitive behavioural therapy. A further meta-analysis study researching the efficacy of psychological treatments concluded that headache was reduced by 37 to 50%, with no significant difference among treatments (Penzin, Rains, Lipchik & Creer, 2004). Despite this, studies on coping with ETTH (Rollnik et al., 2006; Slettbakk et al., 2006) have not discussed psychological treatments as part of the regime for managing headaches. While this review has considered studies on conventional medication, healthcare, and alternate therapies, it is also worth looking into how social support may contribute to managing headache.

Research suggests that social support acts as a moderator in the experience of stress and, in turn, reduces headache (Martin & Theunissen, 1993). However, this relationship is not as straightforward as perhaps assumed, as the effectiveness of social support is dependent on its quality and how satisfactory it is (Gil, Keefe, Crisson & van Daltsen, 1987). This raises the question of the types of social support individuals with migraine/TTH use and how effective these are when managing headache.

Peters et al. (2004) suggest social support, including families, friends, work colleagues, and other headache patients, to be an adjunct to other management strategies. However, the benefits and details of how this type of support was chosen to manage headaches were limited. For example, a majority of the research suggests that

using family, friends, and work colleagues as social support is not viable; on the contrary, individuals with migraine/CHD (Peters et al., 2004) and women with migraines (Moloney et al., 2006; Rutberg & Öhrling, 2012) have been found not to talk to others about headache due to a perceived lack of understanding among groups. Furthermore, studies exploring migraine and TTH have failed to discuss social support as part of patients' experiences of managing headache (Leiper et al., 2006; Rollnik et al., 2006). Indeed, Martin and Soon (1993) suggest that people with chronic migraines and TTH headaches are less satisfied with various forms of social support when compared with non-headache control subjects.

Some types of social support have nevertheless been reported as being beneficial for managing headaches, particularly instances in which the support is offered by individuals experiencing headaches, as in these cases, headaches are accepted as a part of life (Belam et al., 2005). Support from peers also facilitates the sharing of alternative management strategies and new information (Peters et al., 2004). Headache specialist support groups, such as Migraine Action, have been identified as beneficial by some individuals with migraine/CHD (Peters et al., 2004), alongside headache support groups hosted by neurological hospitals (Belam et al., 2005); however, individuals noted that little is known about the detail of using groups for managing headaches compared to, for example, groups that support asthma sufferers (Belam et al., 2005). Zrebiec and Jacobson (2001) believe that online support groups can address a wide range of health-related informational, emotional, and supportive needs that are not featured as part of managing headaches in the studies of support groups mentioned above. Furthermore, although migraine support groups have been identified, little is known about whether individuals with less recognised headaches, such as ETTH, also make use of these types of groups.

The limited qualitative research on ETTH (e.g., Slettbakk et al., 2006) has shown that formal support groups do not feature as part of the experiences of managing headaches in individuals with ETTH. However, there have been cases of informal self-help groups; for example, in Slettbakk et al. (2006), one woman revealed how she had formed a support group with her friends, who had a diverse range of complaints, which was known as ‘the never-mind club’. This allowed for conversation to take place in a friendly and humorous environment, reinforcing the notion of not taking life too seriously and not letting the smaller issues in life cause anxiety. This group served the purpose of promoting shared strength and self-determination within a group of female peers. However, this was only one woman’s experience. In this sense, I am curious as to whether other forms of informal self-help groups are used by individuals with ETTH to manage headaches, or whether they make use of formal migraine support groups. As previous studies have highlighted the dominance of migraine support groups, it is worth considering if individuals with ETTH are also inclined to access online support groups.

Peters et al. (2004) discuss self-help and lifestyle strategies for managing headache, in which those affected take the initiative and contribute actively to their own headache management. The researchers focused on medication choice and the triggers that cause and cure headache, as well as associated lifestyle, diet, sleep, and stress control. Peters et al. (2004) emphasised how using these strategies required the person to employ their own resources in the management of headache; however, they presented little discussion on the specifics of such management strategies. A wealth of cross-sectional research has substantiated many of the common precipitating factors in the onset of migraine (Wang et al., 2013; Wöber et al., 2006) while a smaller number of studies have focused on the triggers of ETTH (Bendsten & Jensen, 2008; Rasmussen et al., 1992; Ulrich et al., 1996). While these studies provide a list of triggers that are common to the onset of migraine and ETTH, it is important to consider how an

individual with TTH/migraine will use the knowledge of triggers in the management of their headaches.

Phenomenological-based research on migraine has provided useful insights into how the management of triggers can promote control over migraine. For example, in Ramsey (2012), women experiencing migraines noted how avoiding triggers such as coffee and chocolate meant that they felt in control, as they perceived themselves to be always on guard against the possibility of a migraine attack. The association between active avoidance of potential triggers and perceptions of control has also been found among adolescents with migraine (Helvig & Minick, 2013). Rutberg et al. (2013) further associate the strategy of identifying and avoiding triggers as conveying a sense of feeling safe against migraine among both males and females. A study carried out by Moloney et al. (2006) explores how some women with premenopausal migraine found it challenging to manage triggers since the type of triggers were always changing. This is in contrast with many studies implying that individuals identifying triggers can eliminate or avoid them with no problem, thus inferring a simplistic relationship (e.g., Helvig & Minick, 2013; Ramsey, 2012; Rutberg et al., 2013; Slettbakk et al., 2006).

Studies on migraine have also shown that individuals act to reduce stress, as this is widely accepted to be a precipitating factor for migraine, by addressing and changing their lifestyles. For example, women with migraines have been found to adopt stress management behavioural strategies such as exercise and relaxation (Moloney et al., 2006; Rutberg & Öhrling, 2012). While these coping strategies have been shown by these studies to benefit women in terms of reducing stress, there may also be some less positive impacts in other domains of an individual's life. For example, Helvig and Minick (2013) found that reducing social encounters and other day-to-day activities increased 'therapeutic rest', referred to as individuals with headaches removing themselves from daily life, which they claim was an effective way of coping with

having too much on one's mind or being physically tired. However, removing oneself from others also resulted in missing out on social activities. Meyer (2012) observes how individuals must submit to bedrest when having a migraine, thus implying that the individual has no choice in the matter; however, this fails to consider the impact of avoiding or not dealing with the stressors around them.

Other studies, such as Moloney et al. (2006), have highlighted other ways in which women experiencing migraines have been proactive in terms of removing stressors, with one woman noting how she quit her job to make her migraines stop. This research neglects to address how individuals who cannot eliminate stressors manage and cope. Neither does it address how individuals experiencing less severe headaches cope with triggers and making lifestyle changes.

Slettbakk et al. (2006) carried out a phenomenological study looking at the shared experiences of fifteen women with ETTH where they reported on the cognitive and behavioural strategies used to manage headache. This is the only qualitative study in this review which exclusively focused on ETTH, whereas most qualitative studies reported on the experiences of managing migraine (Moloney et al., 2006; Rutberg et al., 2013; Rutberg & Öhrling, 2012), migraine/TTH (Leiper et al., 2006) and migraine/CHD (Peters et al., 2005) collectively.

The researchers found that women managed ETTH by strove to balance triggers to ETTH by using cognitive and behavioural strategies. For example, behavioural strategies included, drinking enough water so that they did not experience dehydration, balancing body temperature (for example, when feeling too hot, cooling down using cold packs and showers), increasing or decreasing sleep, ensuring that their level of coffee intake was managed appropriately, balancing foods so that their diet included wholesome foods, and engaging in regular exercise to stay fit. A smaller part of the discussion related to how women used cognitive coping strategies, such as relaxation,

managing commitments, being realistic about what they could do, and addressing pace, as a different approach to taking charge of their lives.

I intend to further the work of Slettbakk et al. (2006) in the following ways. I will firstly interpret what the experiences of medication and accessing health professionals means for individuals managing ETTH, if discussed by them. Slettbakk et al (2006) made the decision not to report on these experiences, whilst qualitative studies looking at CHD/migraine (Peters et al., 2005), migraine (Moloney et al., 2006; Rutberg et al., 2013; Rutberg & Öhring, 2012) discussed how medication and healthcare was central to the experiences of individuals in managing headache. It will therefore be interesting to explore this with individuals with ETTH.

Additionally, whilst the researchers revealed how women used several behavioural and cognitive strategies to effectively manage ETTH by balancing triggers, I would like to further develop these findings by exploring experiences which may allude to new perspectives which highlight struggles individuals may face when managing triggers. Qualitative studies looking at migraine/TTH have shed light on the obstacles individuals face when managing migraine/TTH (e.g., Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhring, 2012). Therefore, it will be interesting to explore this in individuals with ETTH.

Furthermore, ETTH is a physiological response to stress, anxiety, depression, emotional conflicts, and fatigue (e.g., Cathcart, Petkov & Pritchard, 2008; Constantinides et al., 2015; Diamond, 1999; Frith, 2016). It would therefore be interesting to explore what stress means for the individual and its association with managing ETTH. This builds on Slettbakk et al.'s (2006) work where addressing pace and commitments in life were identified.

Moreover, whilst Slettbakk et al., (2006) decided to focus on women with ETTH, Rollnik et al. (2003) suggests that gender differences can exist when coping with headaches. Therefore, it would be pertinent to explore experiences of men and women.

Finally, Slettbakk et al (2006) used focus groups which are commonly used in phenomenological research as they stimulate discussion and new perspectives (Bradbury-Jones, Sambrook & Irvine, 2009). I would like to explore ETTH by taking an idiographic approach to seek essential characteristics of the experience of ETTH where the individual describes their experience in an uncontaminated way (Bradbury-Jones et al., 2009). An idiographic approach which is aligned to interpretative phenomenological analysis (Smith et al., 2009) will be used.

Study Rationale

A synthesis of the findings from the available studies suggests that the experience of TTH/migraine is not restricted only to headaches and the physical symptoms identified by the ICHD-3 beta criteria (IHS, 2013), but also extends to how the varied experiences of the impacts of these physical symptoms on the physical, psychological, and social functioning of those affected (Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006; Peters et al., 2005; Ramsey, 2012; Rutberg & Öhrling, 2012). A key determinant of how TTH/migraine impacts the individual is how the individual copes with and manages headaches. Studies have outlined a variety of techniques for managing TTH/migraine, including medication use, access to healthcare, CAMs, social support, self-help, and lifestyle changes (Litt & Tennen, 2015; Peters et al., 2005). Furthermore, how an individual uses their own emotional and cognitive strategies to cope with TTH/migraine also influences how successful they are in managing TTH/migraine (Rollnik et al., 2001; Wittrock & Myers, 1998).

Whilst these studies provide useful findings in the management of migraine/TTH (e.g., Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006;

Ramsey, 2012; Rutberg & Öhrling, 2012) or look at the chronic subtype of TTH discussed collectively with migraine (Peters et al., 2005; Ruiz de Velasco et al., 2003), I will focus exclusively on ETTH. In turn I will build on these studies by exploring the experience of both the impact and management of ETTH. Studies looking at TTH/migraine portray static descriptions of how individuals experience migraine/TTH, the chosen methodology of which did not allude to the fluidity of experiential and situational factors that may change over the course of experiencing the headaches (Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006; Peters et al., 2004; Ramsey, 2012; Rutberg & Öhrling, 2012). I will therefore add to these studies by opening up perspectives in the fluidity of experiential and situational factors that may change over the course of experiencing the headaches. In the same vein, while many of the studies found an association between coping strategies and health seeking/avoidance behaviour (Leiper et al., 2006; Rollnik et al., 2001; Wittrock & Myers, 1998), they polarised coping and health behaviours without discussing how individuals may oscillate between the two. Additionally, the ICHD-3 beta classification and GP diagnoses reduce experience to the level of symptoms (Waldie, 2015), and many of the studies looking at experiences of TTH/migraine use the term 'patient', considered by some to be reductionist, thus minimising the experiences of those affected (Conrad & Barker, 2010). Furthermore, the one study exploring ETTH (Slettbakk et al., 2006) describes coping strategies used by women. I will build on this work by exploring the complexities and consequences of adopting these strategies.

Existing research alludes to psychological issues in headache-prone individuals who experience medication overuse and dependency (Frith, 2016; Jonsson et al., 2013). The one study that looked at the experiences of ETTH excluded the experience of medication and accessing healthcare services (Slettbakk et al., 2006). This, in turn, begs

the question of how individuals use medication and access healthcare services as part of their experience of managing ETTH.

This thesis aims to generate rich data relating to how people live with and manage ETTH, the most prevalent yet neglected headache disorder (Waldie, 2015). Specifically, this study will focus on how the individual gives meaning to experiences of living with and managing ETTH. This will be done by focusing on individuals' experiences of symptoms as knowledge resources with the potential to shed light on how people live with and manage ETTH (Malterud, 2000).

Chapter Three

Methodology

Methodology

Rationale

In Chapter Two I highlighted that research into ETTH is limited (Rollnik et al., 2001; Slettbakk et al., 2006) when compared with studies on migraines (Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhrling, 2012) and CTTH (Peters et al., 2005; Ruiz de Velasco et al., 2003). Further, studies on managing headaches have focussed on migraines (Moloney et al., 2006; Rutberg & Öhrling, 2012) or chronic headaches (Peters et al., 2004), with only one study looking at the shared experiences of self-initiated coping strategies in women with ETTH (Slettbakk et al., 2006), albeit excluding mention of medication and the use of healthcare. Conversely, Peters et al. (2004) focused predominantly on medication and healthcare in the management of CHD/migraine. From this perspective, I intend to build on the work of Slettbakk et al. (2006) and Peters et al. (2004) by including all aspects of managing ETTH which are part of individuals lived experiences. Further, the experience of living with ETTH has not been examined in the studies I reviewed, although this approach has been used in relation to living with migraine (Ramsey, 2012; Rutberg & Öhrling, 2012). In this study, I will introduce a focus on both the lived experiences and managing ETTH by taking an idiographic approach. To achieve this aim, I have chosen a qualitative research approach, which allows for an examination of patients' experiences as knowledge resources (Malterud, 2000), and adopt IPA as a research philosophy (Smith et al., 2009) in order to place individuals with ETTH as the experts when interpreting their own experiences of living with and managing ETTH (Smith et al., 2009).

Choosing Qualitative Paradigm

Here I present a summary of the assumptions relating to the methodology, epistemology and ontology adopted in the research (a more detailed discussion can be found in the

Methodological Chapter in Appendix C). Epistemology is “a way of understanding and explaining how we know what we know” (Crotty, 2003, p. 3) and is also concerned with providing a philosophical grounding for what kinds of knowledge are possible and how we can ensure they are both adequate and legitimate (Maynard, 1994). Ontology is concerned with “what kind of world we are investigating, with the nature of existence, with the structure of reality as such” (Crotty, 2003, p. 3). Qualitative inquiry complements a social constructed ontology where I see ETTH being complex, dynamic and socially constructed (Denzin & Lincoln, 2008).

I selected constructivism as the research paradigm which directed my epistemological and ontological positioning, wherein knowledge is dependent on who is constructing it, thus leading to multiple realities and subjective meanings (Andrews, 2012; Rohleder & Lyons, 2014). Qualitative methodology is akin to social constructionism in that it rejects the idea that knowledge is objective reality (Launer, 1996). This contrasts with the positivist paradigm, where knowledge consists of verified hypotheses which enable the prediction and control of the phenomena (von Wright, 1971) under investigation; this paradigm is associated with reductionism and determinism, where the researcher is the expert. This approach sits with my epistemological positioning.

A qualitative inquiry enabled the individual and myself to construct meaning about ETTH within the context of a social world which is bounded with layers of meaning originating from the diversities in the contexts of human experiences and interpretations (Denzin & Lincoln, 2008). This had the potential for providing insight into the perspectives and behaviour of people with headaches in their own words (Peters et al., 2002) where I maintained a multidimensional understanding of ETTH which goes beyond an everyday or common sense awareness (Curry, Nembhard, & Bradley, 2009;

Kearney, 2001; Shepard, Jensen, Schmoll, Hack, & Gwyer, 1993). This sits with my ontological positioning

Having decided that qualitative research was required, the next stage was to consider the qualitative paradigm/strategies that would give me the flexibility to explore the experiences of living with and managing ETTH.

Choosing IPA. IPA was the most suited qualitative paradigm to support the aims of this study where I wanted to explore what it is like for the individual to live with and manage ETTH based on “pain is whatever the experiencing person says it is” (McCaffery, 1968, p.95). This is akin to IPA where there is no one objective truth but instead there are multiple truths, each of which are dependent on the what each individual sees as important in their lived experience of managing ETTH, their interaction with the world, situational contexts and others around them (Smith et al, 2009). The choice of IPA for this study was further appealing when compared with other qualitative paradigms which I summarise below (refer to Appendix B for a discussion on my reasoning for using IPA as a method of inquiry compared to other qualitative methods of inquiry).

Although I appreciate the role language plays in participants describing their experiences (Jorgensen & Phillips, 2002), I did not want to examine and analyse how individuals use language to describe experiences of ETTH, which is the aim of discourse analysis (DA) (Starks & Trinidad, 2007). Instead, I wanted to focus on how individuals ascribe meaning to the way in which they interact with the environment through gaining access to their inner world, which is akin to IPA (Smith et al., 2009).

My intention was not to conceptualise and develop theory from the data, which is akin to Grounded Theory (GT) (Glaser & Stratus, 1967, as cited in Samik-Ibrahim, 2000), rather I wanted to utilise the IPA approach of creating a rich description of the experience of living with and managing ETTH (Smith et al., 2009). I rejected GT as this

would have limited my investigation to the social problems/situations that the individuals adapt to (Glaser & Strauss, 1967, as cited in Samik-Ibrahim, 2000). This in turn would have deterred me from exploring the experiences particularly aspects that fall outside of social settings and interactions. I also found that having to ‘adapt’ would have restricted my exploration of experiences where individuals may have not been willing or unable to adapt, which would have moved me away from understanding the experience and situation as lived by the participant, which changes over time and is more in line with IPA (Smith et al., 2009).

More a tool than a method (Boyatzis, 1998, as cited in Braun & Clarke, 2006), Thematic Analysis (TA) is guided by phenomenology during data collection where the primary goal is to identify, analyse and report patterns across participants (Braun & Clarke, 2006). This did not fit with my aim of identifying patterns within each participant and engaging with the everyday experiences of each participant’s life, with an idiographic focus on creating a biographical image of the participant’s lived experience. This is akin to IPA (Smith et al., 2009) whereas TA aims to create a more generalised view where pattern-based analysis is conducted (Clarke & Braun, 2013).

Choosing phenomenology. According to Rossman and Rallis (1998), phenomenology aims to study how people make sense of their lived experience, with Schwandt (2000) stating that phenomenology allows researchers to focus on the everyday, inter-subjective world as constituted from the participants perspective (Schwandt, 2000). This philosophical principle of phenomenology was appealing to me as I wanted to explore how individuals made sense of their living experiences and management of ETTH.

The choice of ‘interpretative’ phenomenology. IPA is different to using phenomenology alone, where it would not have been possible to access the cognitive world of the individual through interpretation (Creswell, 2013). In turn, I found IPA to

be the most suitable method since “without phenomenology there is nothing to interpret and without hermeneutics the phenomena cannot be seen” (Smith et al., 2009, p. 37).

I wanted to move beyond the participants’ descriptions of their experiences to how both the research and I interpreted these experiences. According to Brocki and Wearden (2008), and Smith et al., (2009), individuals engage in self-interpreting activity when attributing meaning to their experiences, thereby suggesting that the understanding of a phenomenon is always open to interpretation. Secondly, individuals are engaged in a self-interpreting activity through attributing meaning to their experience. In this way, the participant is afforded the status of an expert. The researcher then adds a further level of interpretation regarding their experiences in the process of analysing data. This is known as the double hermeneutic approach (Smith et al., 2009).

In seeking to capture, immerse myself in, and interpret the lived experiences of the individual, I reject Husserl’s transcendental approach to phenomenology. This approach suggests that I, as the researcher, can suspend ‘bracket’ my own assumptions and experiences to get to one universal truth of what it is like to experience living with and managing ETTH (Larkin and Thompson, 2012). Bracketing is a methodological device of phenomenological inquiry that requires deliberately putting aside one’s own beliefs about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation (Carpenter, 2011b). I side with Heidegger’s existential view on phenomenology where it is impossible for myself, as the researcher, to suspend my own assumptions and experiences, as my understanding is bound up by my ‘being in the world’ which Heidegger refers to as, ‘Dasein’ (i.e., people, things, knowledge, language, relationship, culture (Allen-Collinson, 2009; Heidegger, Macquarrie & Robinson, 1962; Larkin, Watts, & Clifton, 2006; Shaw, 2010)).

Being reflexive. Throughout this study, I wanted to be aware of how my own subjective experiences, personal processes and biases had the potential to impact the research by engaging in reflexive thinking (Creswell, 2003; Finlay, 2003; Heidegger et al, 1962). By maintaining a reflexive journal, and discussing my thoughts and ideas with my supervisors, mentors and peers, during data collection (interviews) and analysis. Smith et al (2009) and Shaw (2010) state that it is not possible or necessary for the researcher to suspend their assumptions or experiences, but instead adopt a reflexive attitude when carrying out qualitative research such as IPA. This allowed me to remain as close as possible to the participant's interpretation of their experiences, whilst bringing into my conscious awareness, and making explicit, my own experiences, assumptions and potential biases (Finlay, 2003). Throughout this study, I was aware of multiple truths which derived from participants (during interview) and my own (during data analysis) interpretation which have been influenced by our own subjective experiences of being in the world (Heidegger et al, 1962).

Maintaining a reflexive attitude throughout this study facilitated me to bring into my conscious awareness my subjective experiences and assumptions Creswell (2013) in the following ways. When discussing the initial semi-structured interview schedule, I became aware that one of my questions 'how do you actively cope' was linked to the assumption that participants 'actively coped'. Having brought this into my awareness, the final semi-structure interview scheduled comprised of two broad questions 'tell me about your experience of ETTH' and 'tell me about your experiences of managing ETTH'. This enabled each participant to understand their own experience of living with and managing ETTH without being swayed by my assumption that participants 'actively coped with ETTH' during the interview (phenomenology). Further, I wrote about my thoughts, experiences of ETTH in my journal during data collection (interview) and discussed these with my mentor which enabled me to express

my own feelings without swaying the participant during the interview (Smith et al., 2009) (see Appendix A Reflexivity Chapter for a detailed discussion).

During data analysis stage, I entered the cognitive world of the individual through interpretation (Creswell, 2013), firstly by making sense of how the participant understood their experience of ETTH, as lived and understood by them, and then how I as a researcher interpreted the participants' interpretation of their experiences (double hermeneutics) (Smith et al., 2009). I made regular use of my reflective journal and discussions with my supervisors, mentors and peers discussions which helped me become aware of how my own training in health psychology and experience of headache, moved me away from the individuals lived experience of ETTH. By being aware of this, diverted my attention back to the world of the participant and their experience of ETTH. During the latter stages of data analysis, I become aware and make explicit how my training and reading in health psychology (Moustakas, 1994) impacted data analysis (Tufford & Newman, 2012). This enabled me to exert my positionality throughout this research in maintaining a social constructivist positioning as a trainee Health Psychologist (see Appendix A Reflexivity Chapter for a detailed discussion).

Idiography. IPA supports an idiographic approach (Smith et al., 2009) which also appealed to me where I, as a researcher, could focus in detail on each individual experience during data collection and data analysis, thereby allowing for rich descriptions of experience. in-depth analysis of single cases and examined individual perspectives of ETTH in their unique contexts (Pietkiewicz & Smith, 2014). Taking an idiographic approach enabled me to remain faithful to the individual through illustrating the lifeworld of participants who recounted their experiences of ETTH whilst also illustrating more general themes (Smith & Eatough, 2006).

Research Design

I used one-on-one semi structured interviews, where the participants could describe and give meaning to their lived experiences of the phenomena; this is what Heidegger describes as the first part of the hermeneutic cycle (Heidegger et al., 1962). During this stage, I bracketed my preconceptions so that the participant, as the expert, was not swayed by my ideas. Probes were designed to prompt participants to discuss their experience of ETTH in more depth. In the second stage, data analysis was carried out, through which I engaged in interpretive activity to ascertain the meaning of the phenomena (Smith & Osborn, 2008) from the perspective of a 'trainee Health Psychologist'. I embrace the underpinning of IPA in recognising that a perfect understanding of the essence of ETTH will always remain hidden due to the interpretative activity that both myself and the participants have engaged in (Moran, 2000).

The current study aimed to address these gaps by exploring the experiences of living with and managing ETTH. IPA helped me shape my questions, which emphasised the lived experiences of the participants, framed broadly and openly, thus further encouraging me to explore how participants perceive their situations (Smith & Osborn, 2008).

More specific objectives included generating data to improve the understanding of the following topics:

- How do individuals experience ETTH?
- What impact does ETTH have on their cognitive functioning, emotions, and behaviour? This will include a consideration of how the experience of ETTH may impact different aspects of the individuals' day-to-day functioning.
- What impact does ETTH have on social functioning?
- How do individuals manage ETTH?

Participant sample and demography. A common criticism of qualitative methodology is related to its dependence on small sample sizes, which renders it incapable of generalising conclusions (Hamel, Dufour & Fortin, 1993). This issue raises the relevance of being explicit about the steps taken to optimise the methodological qualities and rigour of the adopted approach (Yin, 1994), including the need to explicitly define and justify the sample size (Koch, 2006). The size of the sample in this study was nine participants. According to Starks and Trinidad (2007), one to ten interviews are a sufficient range for phenomenological studies, and Smith et al. (2009) suggest four interviews for professional doctorates using IPA. The sample size of nine participants allowed me to maintain an idiographic focus and explore multiple perspectives, with the aim of generating a detailed and multifaceted account of the experiences of the phenomena (Larkin & Griffiths, 2004).

In line with guidance from Altheide and Johnson (1994), rigorous attempts were made to recruit participants. The study was advertised on the social networking sites Psychologist in the Pub and Facebook.com, which, according to Thompson (1997), provides a researcher with an ever-expanding set of potential contacts (Vogt, 1999) (see Appendix D for the research advertisement, which was circulated on-line). This technique helped me to tap into community groups, with the benefit of accessing individuals with ETTH who would not necessarily access social networking sites. I was unable to recruit from specialist headache sites as they hosted studies which recruited individuals with migraines and cluster headaches. My recruitment method was different from that of many studies I reviewed, in which individuals were referred from neurological settings. Volunteers with ETTH self-referred themselves to this study.

The sample was selected purposively from volunteers who self-referred themselves with ETTH (see Appendix E for the study inclusion/exclusion criteria). Purposive sampling is common in phenomenological research, as it selects individuals

to the study based on their knowledge of the phenomena so that they can share such knowledge (Carpenter, 2011b; Crotty, 1996) and an insight is provided on the phenomena, which is consistent with IPA's orientation (Smith et al., 2009).

Purposive sampling was used to select individuals who had experience of the phenomena. From the fifteen volunteers who expressed an interest in taking part, four had self-referred with migraine, and thus did not meet the inclusion criteria (see Appendix E for the study inclusion/exclusion criteria). This makes the study distinct from the two previous studies of ETTH reviewed in Chapter Two (i.e., Rollnik et al., 2001; Slettbakk et al., 2006) which included individuals with 'headaches'. The remaining two volunteers had ETTH and chronic fatigue syndrome (CFS). These two declined to take part, as they considered their ETTH secondary to their experience of CFS. Therefore, my selection criteria allowed me to focus on individuals who had experience of the phenomena in question, enabling me to obtain a homogenous sample which, according to Smith et al. (2009), increased the potential of the study to address the research question in a meaningful way.

The nine participants were one male and eight females with an age range of 30 to 55, with mixed ethnicity, and all fluent English speakers. The inclusion criteria for this study was that individuals had to have had ETTH for a minimum of three months; two participants had had ETTH from childhood and 7 from early adulthood. Only one of the participants had been diagnosed with ETTH (see Figure A for a further demographic breakdown of the participants and Appendix F for further details of participant demography). Attaining a gender balance was difficult, as 14 out of the 15 volunteers were females, which made me question whether males were less forthcoming or were less willing to acknowledge ETTH. This is in line with many of the studies reviewed, which had an over-representation of females. The two qualitative studies looking at the lived experiences of migraine sufferers (i.e., Ramsey, 2012; Rutberg et

al., 2012) and the experiences of coping strategies for ETTH (Slettbakk et al., 2006) were comprised of females.

Table 1

Participants' demographic breakdown

Participant*	Gender	Age	Ethnicity	History of ETTH
Anne	F	30	British	No formal diagnosis. Since early adulthood
Barbara	F	45	British	Formal diagnosis, November 2013. Since childhood
Lynn	F	35	Greek Cypriot	No formal diagnosis. Since undergraduate studies
Angela	F	38	British	Last 20 years. No diagnosis
Natasha	F	52	Irish	Since early adulthood. Formal diagnosis, 30s
Rita	F	34	British Asian	No formal diagnosis. Since undergraduate studies
Jason	M	37	British	No formal diagnosis. Since beginning work
Samantha	F	55	British	No formal diagnosis. Since beginning work

* Pseudo-names have been used to refer to each participant

Pilot study. I piloted the interview with one individual, which helped me hone my skills in using open-ended questions, attentive listening, and prompts (Jovchelovitch & Bauer, 2000). I become sensitised to the research question and topic and to IPA (Smith et al., 2009), thus ensuring the appropriateness of my proposed methodology (McLeod, 2011). There were no major aspects that I had overlooked relating to the

interview schedule (see Appendix G for the semi-structured interview schedule) (Polit, Beck & Hungler, 2001), but I became mindful that, at times, I would respond to the participants (Smith et al., 2009) as I would with service users, which I had to resist. I was happy to proceed with the audio recording of interviews and sending the audio files to a professional transcriber, which worked well.

Procedure

Data collection. Since the phenomenological approach seeks to understand the lived experiences of participants (Morse & Field, 1996), in-depth interviews were selected to attain rich and personal data of the experience of the phenomena. The research design, including the use of semi-structured interviews (see Appendix G for the semi-structured interview schedule), was developed in line with the recommendation made by Smith and Osborn (2008), who suggest that semi-structured interviews are an exemplary method for IPA; in this way, I found they supported participants in being the primary experts regarding their experiences of the phenomena (Alexander & Clare, 2004).

The interview began with a broad, open-ended question about the participants' experience of living with ETTH. That question was followed by a second broad open-ended question asking the participants about their experiences managing ETTH. I used probes to guide the participants, going from a general view to more specific lived experience (Smith & Osborn, 2008). For example, I would say, "tell me about your experience of living with ETTH", and a typical answer would be, "I get pain". This answer did not capture the lived experience, so I used a probe to capture the lived experience with the following question: "you have said that ETTH means you live with pain - can you tell me what this pain means for you?" The following probes were used, which helped the participants talk about their lived experiences of ETTH: Tell me how that impacts on you? How does that make you feel? How does that impact on your

interactions with others? Why is that? Tell me a bit more about that, that's interesting? I was mindful not to interrupt the participants, and I made minimal use of the probes so that the participant had a strong role in the interview (Smith & Osborn, 2008). In this sense, I also made use of prompts such as 'hmmm', and head nodding as much as possible in order to encourage the participants to carry on with their description of experiences. In this respect, I was as non-directive as possible while guiding the participants into the research area (Crotty, 1996).

Data analysis. While Smith, Jarman and Osborn (1999) explicitly state that a prescriptive methodology is not appropriate for IPA, Smith et al. (2009) provided six steps for IPA data analysis for novice IPA researchers like myself. This helped to instil confidence in my ability to appropriately use this approach and are outlined below:

Step 1: Reading and re-reading. Although normally, familiarity with the material is gained during the transcription process, in this study I used a professional transcriber. Subsequently, I listened to the audio files and read and re-read the transcripts several times. This process helped me become familiar with the emotions and the living world of each participant.

Step 2: Initial noting. It was important to return to each transcript line-by-line and in doing so I made descriptive, conceptual, and linguistic notes. I extracted phrases that directly pertained to the investigated phenomena while staying close to the participant's meaning. This was a meticulous process (Smith & Osborn, 2008), but it allowed me to further familiarise myself with the participant's lifeworld (Smith et al, 2009). Colaizzi (1978) suggests that at this stage the same or nearly the same statements can be found, and where necessary, repetitions should be eliminated. Transcripts were cut so that similar phrases could be linked together and included only once.

Step 3: Developing emergent themes. I sought to identify emergent themes as I shifted from the transcript to my comprehensive notes, which were grouped into

themes. At first I felt uncomfortable when I had to break away from the flow of the transcript. Smith et al. (2009) referred to this as an analytical shift. Some of the themes that began to emerge pertaining to the phenomena were coping, defence mechanisms, functioning, and health behaviours, and during this analytical shift my health psychology lens came into play.

Step 4: Searching for connections across emergent themes. At the end of this stage, I had identified a significant number of related themes, which felt good as I had brought the experience for each participant together again. Some of the connections were, for example, the link between coping and defence mechanisms and between protecting and harmful health behaviours. These themes began to emerge as subordinate themes.

Step 5: Moving on to the next case. The above steps were repeated. I retained my focus on the participant's transcript.

Step 6: Looking for patterns across the cases. At this stage, all the themes that were identified for each transcript were linked together, and the most common themes applicable to all the participants were put together. On reflection with my supervisors, I found that coping was the central superordinate theme. The list of subordinate and superordinate themes can be found in Appendix H. In addition, see Appendix I for an exemplar transcription that has been fully analysed.

Ethical Considerations

This study was approved by the University Research Ethics Committee at the University of the West of England (see Appendix J for ethical approval).

It was important to be aware of the emotional, sensitive, and ethical aspects in undertaking this research. The interview process had the potential to reawaken sensitive and emotional issues in the participants and for them to experience distress during the interview. Time was set aside at the end of the interview to debrief (see Appendix K for

further details regarding debriefing). Participants agreed to take part in the study voluntarily, thereby respecting their autonomy (Beauchamp & Childress, 2001). Informed consent is a central ethical issue, and working within the guidelines of the British Psychological Society (BPS, 2014), I ensured that the aims and purpose of the research were clearly outlined in the information sheet (see Appendix L) which accompanied the consent form (see Appendix M). Indeed, Allmark et al. (2009) highlight “a danger of participants being drawn into the research on partial information and then feeling obliged to continue” (p. 6) as informed consent is problematical in qualitative research where direction is largely unknown (Ramos, 1989). In this sense, as informed consent is on-going in qualitative research (Party, 2008), I re-visited consent during the interview.

It is important to carefully consider and to discuss with participants the potential risks of participating in the study, which included re-visiting sensitive life experiences which could be emotional (Clark & Scharf, 2007). Beneficence is a fundamental ethical principle, endorsed by the BPS (2009), which encompasses, above all, doing no harm. In this sense, participants’ reactions were monitored during the interview to see how they were faring, and they were frequently asked how they were feeling; in addition, all participants were aware that they could stop the interview at any time, but none of the participants did so.

The BPS (2014) emphasises the rights to privacy and protection. I was acutely aware of the difficulties in safeguarding the confidentiality and anonymity of participants as there is no guarantee prior to the interview that participants will be aware of what they might reveal and the potential impacts of disclosure (Raudonis, 1992). The one-on-one nature of such studies makes full assurances of anonymity impossible for the researcher (Smith et al., 2009), but only limited personal information was sought, i.e., first name, age, and residence. Participants were interviewed in a psychology

interview room at my place of work. Carpenter (2011a) notes the difficulty in maintaining confidentiality where some of the participants could be familiar with others, as details given to verify and support themes may reveal the identity of participants. I was aware of this issue and therefore allocated pseudo names to replace names in order to identify individuals during transcriptions (Corden & Sainsbury, 2006) and any information that referred to a name or place of work was changed. To enhance anonymity and confidentiality, the transcripts were sent back to each participant to see if they wanted to change any part of the transcript which revealed their identity, but all the participants were happy with the sent transcripts (see Appendix N for e-mail member checking). I made participants aware that audio recordings, which all participants verbally consented to, were being sent to a professional transcriber who lived outside of the West Midlands area and did not have any affiliations to any head pain societies (Damianakis & Woodford, 2012). All the paperwork was locked in a cabinet in my office, and all the digital audio recordings were stored on a password protected file (Corti, Day & Backhouse, 2000), which only I could access.

Chapter Four

Results

Results

Interpretative phenomenological analysis (IPA) of the nine transcripts generated three superordinate and 9 subordinate themes (see Table 2) (see Appendix 0 for a detailed breakdown of all themes). In this Chapter, individual participant representations of each theme are presented interpretatively. The three superordinate themes are: (1) the essential and versatile use of coping strategies in the experience of living with and managing ETTH; (2) the intricate (entangled) relationship between functioning and (dys)functioning; and (3) a love-hate relationship with health professionals and medication. While each theme has been presented separately, they overlapped in the narratives of the participants.

The Essential and Versatile Use of Coping Strategies in the Experience of Living with and Managing ETTH: Superordinate Theme One

The first theme across the interviews drew on the essential and versatile use of coping strategies in the experience of living with and managing ETTH. I captured this as the subordinate themes of ‘coping strategies that are maladaptive for the individual’s health and well-being’, ‘coping strategies that are adaptive for the individual’s health and well-being’, ‘the use of self-care health behaviours to achieve self-regulation and ‘the use of defence mechanisms as a way of coping’.

Coping strategies that are maladaptive for the individual’s health and well-being.

You kind of feel like you’re telling the same story again ... ‘Ah, I’ve got a headache again...’ and then it’s, like, just stop with the headache ... I would be sick of talking about it ... so I just go on like there is nothing wrong (Rita, L521 – L523 & L530 – L531).

Table 2: Superordinate and subordinate themes emerging from IPA transcripts

1. The Essential and Versatile Use of Coping Strategies in the Experience of Living with and Managing ETTH	2. The Intricate (Entangled) Relationship between Functioning and (Dys)functioning	3. A Love-Hate Relationship with Health Professionals and Medication
1a. Coping strategies that are maladaptive for the individual's health and well-being	2a. The relationship between functioning and psychological (dys)functioning	3a. Unhealthy and unhelpful relationship with health professionals and medication
1b. Coping strategies that are adaptive for the individual's health and well-being	2b. The relationship between functioning and emotional (dys)functioning	3b. Helpful and healthy relationship with health professionals and medication
1c. The use of self-care health behaviours to achieve self-regulation	2c. The relationship between functioning and behavioural (dys)functioning	
1d. The use of defence mechanisms as a way of coping		

Rita had an inherent fear that revealing ETTH to others would result in her being labelled as a 'moaner' and that her public self would be shamed, e.g. 'just stop with the headache'. To cope with this, Rita did not disclose her ETTH but hid her true self through pretence 'go on like there is nothing wrong.' Later, Rita discussed how this adversely impacted her, where she felt isolated and her private self coped by self-medicating with pills and 'sugary foods', which increased ETTH.

Like Rita, Lynn did not disclose to 'colleagues' how her work increased ETTH: 'It's been a stressful period, trying to get things done in a short space of time. I am

constantly worrying, always feeling stressed that I am not good enough, which makes my headaches worse' (Lynn, L12 – L14).

Lynn's headaches were symptomatic of her emotional distress and her inability to control her emotions at work, which were associated with making her 'headaches worse'. At another level, headaches represented Lynn's negative view of the self functioning at work – 'I am not good enough with my work' – thus, depicting low self-worth. Lynn coped by neglecting care of the self and instead replaced this with work:

During this time, I could not sleep because of worrying about how much I had to do, so I would wake up in the middle of the night and go straight to the study room and work, even though my head was heavy (Lynn, L20 – L34).

Despite Lynn stating that she could not sleep, she later described how, like Rita, she neglected the care of the self, 'depriving the self from sleep' and self-medicated with 'coffee' to stay awake, which increased ETTH:

I had lots of coffee and Ibuprofen to help me work through the night, but the next day I felt tired and the headache was really bad ... I felt groggy and tired, my headache was bad, and it was my fault (Lynn, L42 – L61).

Lynn's contradiction in stating that she could not sleep and was self-medicating to stay awake at night alludes to a feeling of shame in how her dysfunctional behavioural patterns of 'staying awake and working at night' resulted in ETTH, depicting self-punishment. This also revealed a difference between her public self at work, which 'got on with work without ETTH', and the private self, which 'coped with ETTH through neglect of the self'. In addition, Lynn also blamed herself for causing her headaches, showing how self-critical dialogue went to the heart of Lynn's low self-worth.

In contrast, Anne discussed how not talking about ETTH at work was a sign of strength: ‘it’s the opening up and acknowledging... yeah, that’s where the weakness comes in’ (L246 – L247). At another level, this depicts how Anne was also fearful of how her public self would be perceived by others, if she spoke about ETTH, to be weak and unable to cope at work.

Participants also discussed how they coped with not being in control of ETTH through self-critical dialogue and self-blame, as illustrated by Natasha: ‘it’s like fighting with it [ETTH]... I’m always battling, which scares me, and then I try and get it together... “You’re pathetic... sort yourself out”’ (Natasha, L368 – L375). Like Natasha, Barbara also felt that she had no control over the irregular pattern of ETTH and coped with this by engaging in self-critical dialogue with the self. This has an adverse impact on her emotional well-being, ‘I’m at a wedding and there it comes... I hate it... hate myself more, which makes me feel down... because I didn’t look after myself but was stressed with everyone coming to the wedding’ (Barbara, L402 – L414).

Rita, Lynn, Anne, Natasha and Barbara coped with functioning in life with ETTH (work, social activities, and the irregular pattern of ETTH) by not talking about ETTH. Instead, their private self felt isolated and this was coped with by engaging in critical self-dialogue, self-blame, self-medication, and neglect of the self. This had an adverse impact on the participants’ psychological, emotional, and physical well-being, which increased ETTH. This I captured into the subordinate theme ‘coping strategies that are maladaptive for the individual’s health and well-being’.

Coping strategies that are adaptive for the individual’s health and well-being.

I have the tension headaches under control now ... it’s my recipe, where I’ve learned to relax about things and understand that people around us and at work, we have no control over them. (Angela, L404 – L408).

Angela narrated how worrying less about situations and people resulted in less headaches. For Angela, being self-aware of her emotional investment and lack of control over others and situations (work) resulted in having control over her headaches which was self-empowering. At another level, Angela used positive self-dialogue to reassure and be kind to the self which stopped her from worrying. However, Angela also alluded to how she could shift her attention from the self to situations and others around her, which increased ETTH (as presented in the section above).

Like Angela, Samantha also narrated how she did not psychologically invest in situations in which she could not control:

I'd think about my health more than getting a letter out within a specified period... I'm not saying I'm not doing that... but I ... do as many as I can and have my breaks and stick to my hours (Samantha, L643- L645 & L648 – L650).

In this sense, Samantha psychologically stepped back by removing the self from emotional distress, which she was aware of being a trigger to ETTH: 'I'm not going to stress about it.' Like Angela, this was also self-empowering for Samantha where she could control her emotional and psychological approach to work which reduced headaches. At another level, this also showed how Samantha engaged in nurturing the self by 'stepping back' rather than 'struggling with getting letters out' where Samantha discussed how previously working to tight and impossible deadlines would have resulted in headaches.

Participants also discussed how they coped with ETTH by sharing similar experiences and resources online, as illustrated by Natasha:

Support is important nowadays they've got kind of groups for everything... like these forums on the internet, don't like these sort of things but the ideas are important to...like these

forums....where I can say that how I'm feeling (Natasha, L605 – L621).

For Natasha, online support allowed the self to be honest and discuss her experiences with others who shared similar experiences. This medium allowed her to disclose ETTH without being judged. This was similarly echoed by Lina who narrated how her latest ideas in managing ETTH came from Facebook groups, 'Facebook is great, that where I get the latest ideas from and I can talk with others who get it' (Lina, L278 – L282). For Lina, this awarded a safe environment in which she could talk. Added to this, both Lina and Natasha felt that they had permission to share their experiences and not be shamed.

This theme has depicted how Angela and Samantha coped with situations and others they had no control over (stressors) by engaging in positive self-dialogue and self-reassurance which was associated with self-control. This enhanced their health and well-being and decreased the frequency of ETTH. For Natasha, accessing online support groups was an effective way of managing ETTH. This converged into the theme 'coping strategies that are adaptive for the individual's health and well-being'.

The use of self-care health behaviours to achieve self-regulation

Angela explained how she took cues from her body ('dehydration'), which was a trigger to ETTH, where she cared for the self by ('increasing water intake'), which balanced the physical self ('hydration') – '[I] drink a lot of water to be hydrated ... even when I'm stressed I found that I feel better ... when I'm hydrated ... like trying to have control'. This showed how Angela was self-aware of her body processes – central to the physical care of the self – which reduced ETTH. At another level, this also showed how this increased control for Angela 'trying to have control'.

However, the self-regulation of triggers to ETTH were not consistently adopted by many of the participants, as illustrated by Anne: 'I've probably gone through my

standard list – food, alcohol ... I sometimes just go, ‘screw it’, and maybe it will help’ (L595 – L597). Whilst she discussed how she took care of the self through self-monitoring and self-managing triggers to ETTH and maintaining a balance of stress in her life with exercise, at other times she did not see any point as she believed that by not doing this it would instead help her to relax and reduce ETTH. This shows that whilst Anne strove to achieve self-regulation of triggers to minimise ETTH, at other times she used triggers of ETTH to relax, which in turn neglected the care of the self, which increased ETTH.

Jason testified to the importance of balancing work with behavioural self-care health behaviours, with recreational time spent with his son, which he found regulated his emotions of ‘worry’. In turn, he felt less stressed and his headaches decreased:

If I’m stressing about something and he needs attention, I’m forced to go out with him so he can play. At first, I get stressed ... but I come away with a different perspective after and feel a lot less stressed... better... not having a headache’ (Jason, L760 – L795).

This also alludes to Jason’s high value on his self-worth, where he was self-aware of the need to self-regulate his emotions. This also increased the social functioning of the self, where his work encouraged isolation of the self. For Jason, caring for the self with behavioural activities which moved him away from sitting and worrying about work led to a reduction in headaches.

Samantha spoke about the importance of emotional regulation (balance), which she achieved by not getting caught up in the moment of stress but instead stepping away, which helped in reducing stress and ETTH by drawing boundaries to balance stress at work:

I should have done it a long time ago. I go for my proper lunch break and I go for a small walk when things start getting hectic at work... It helped

me so much so that I haven't had a headache for months now (Samantha, L720 – L728).

This was achieved by taking the self away from 'a hectic work environment', by carrying out behavioural ('going for a walk') and psychological ('stepping away') health behaviours which were caring to the self. This also showed how Samantha placed high value on her self-worth, where she invested her time and energy in focusing on caring for the self.

Samantha, Anne, Angela, and Jason narrated how they strove to achieve self-regulation by carrying out health behaviours that were caring to the self. When self-regulation was continually maintained, this minimised ETTH. This I captured as the subordinate theme 'health behaviours used to self-regulate (balance) ETTH'.

The use of defence mechanisms as a way of coping. Jason coped with ETTH at work by using the defence mechanism denial, 'pushing things to the back of the mind so that I can get on with my job' (Jason, L34 – L35). Whilst this coping strategy was adaptive to his public self's functioning at work, at another level, this was inauthentic to his real self's experience of ETTH.

Barbara rationalised ETTH through social comparisons with others during her earlier experiences of ETTH:

I've had them since a child ... and I was only diagnosed with tension headaches by the doctor a couple of years ago, which is when I began to accept that I needed to do something ... Before that I thought it was pain like everyone else but, really, I was scared that it was a brain tumour or something (L136 – L141).

At one level, this was an adaptive coping strategy that served the function of reassurance to the self. At another level, using rationalisation was maladaptive to her emotional and psychological well-being, where her private self was anxious of a

terminal illness and was socially isolated from professional help. It was only through years of experiencing ETTH that Barbara stopped rationalising and accepted it, which led her to seek reassurance from a health professional.

Later in the interview, like Jason, Barbara narrated how she used denial when getting on with life with ETTH: ‘I’ll still try and ignore it as much as possible, and, yes, sometimes that works and sometimes it doesn’t’ (Barbara, L384 – L383). This shows the interchangeable use of various types of defence mechanisms and moving back and forth between coping with defence mechanisms and denial, dependent on the relationality of the self with situations, experience of ETTH, and the value placed on self-worth.

Unlike Jason, who used denial to cope with work, Anne narrated her use of projection at work: ‘I wouldn’t get any benefit from moaning; I don’t want to hear it, so they don’t. I don’t want people to approach me and think that it’s because of my work, not because I’m an invalid or something’ (Anne, L198 – L203). Anne attached negative connotations to having ETTH and how her public self did not disclose ETTH, which for Anne meant isolation of the emotional self. These negative connotations were self-imposed and were not validated by colleagues, as illustrated by Lynn: ‘Not only would I fear that they would see it as a weakness ... I’d also question whether they’d really be interested at all anyway, but no one has said anything, ever’ (Lynn, L255 – L256).

Natasha also described how she deflected her experience of ETTH at work with the use of humour. Her public self meant that she was secretive about ETTH, putting on a pretence during social interactions:

There were times at work where colleagues and patients would always say to me, ‘You’re not your bubbly self’, or ‘You’re looking ill, withdrawn or a bit quiet’. I would laugh it off and say, ‘Who do you

think I am – somebody else?’ It’s only when I drive home that the pain sets in (Natasha, L393 – L406).

Natasha discussed how her private self was distinguished from her public self in that her private self acknowledged and dealt with ETTH: ‘I face it behind closed doors.’ This resulted in emotional distress, where she ‘felt sad’ that she had to deal with ‘a worse head pain’ after a long day of ‘pretending’. This, like the participants above, exemplified the isolation of the self when coping with the emotional and physical aspects of ETTH.

Like Barbara, later in the interview, Natasha alluded to also using other defence mechanisms. For example, she alluded to the use of rationalisation (like Anne), where she did not disclose ETTH at work. Her secretive public self was shaped by stigma and a negative view of ill-health through the eyes of others:

Some time ago, somebody had a procedure and I heard different people be horrible about how they spoke about this person. Imagine if you told them you had headaches, they’ll be bitching ... So, I gave them no food; I starved them, and told them nothing (Natasha, L464 – L479).

She described how this had impacted on her emotionally and that putting on a façade and pretending to others was emotionally draining for her private self. At the same time, Natasha felt empowered that she did not disclose ETTH to others, and in this sense, they had ‘no ammunition to bitch’ about her.

This theme reflects how Jason, Anne, Barbara, Lynn and Natasha’s public self coped with not disclosing ETTH by using a complex number of defence mechanisms. Whilst this was adaptive in allowing them to function, it became maladaptive where their private self was isolated and became emotionally drained. Further, this depicted the complex and interchangeable use of defence mechanisms I analysed this into a 4-tier

system (Appendix 0), which I captured as the subordinate theme ‘the use of defence mechanisms as a way of coping’.

In summary, participants narrated their versatility in their use of strategies to cope with ETTH, where they swayed back and forth between coping strategies that were adaptive or maladaptive for their health and well-being and the use of an array of defence mechanisms, which I conceptualised on a continuum (see Appendix 0). This was illustrated by Lynn: ‘I took a step back and thought, ‘I’m not getting trapped into that again... stress and headaches...’ I started exploring mindfulness’ (L94 – L96).

The Intricate (Entangled) Relationship between Functioning and (Dys)functioning: Superordinate Theme Two

A second theme that emerged from the interviews was how the participants’ functioning with ETTH was intertwined with emotional, behavioural, and psychological dysfunction of the self.

The relationship between functioning and psychological (dys)functioning.

I tend to worry excessively about things going wrong when I start to think of something not being done on time ... I foresee problems which often don’t happen, which increases my headaches (Jason, L71 – L75).

Jason’s functioning of ‘working on a task’ was approached by psychological dysfunctioning, ‘foreseeing problems’, which he could not control (‘I try and push these away’). This impacted on Jason’s emotional distress – ‘get stressed and ... more tense’ – which increased his headaches. Jason’s psychological dysfunction impacted on his self-esteem, where he felt ‘inadequate’ and feared ‘failure’. At one level, Jason’s public self at work of being good at his job was different to his private self where he constantly worried, which relates to low self-esteem.

Jason went on to discuss how he could not control his negative thoughts (psychological dysfunction). In this sense, the self was in constant battle with these

thoughts. For Jason, this was frustrating as he wanted to enjoy work but instead felt that he was always ‘stressed’ and could not ‘switch off the thoughts’ as they ‘don’t go away’. For Jason, this became emotional during the interview, where he expressed how his public self disguised his private self’s psychological struggle: ‘No one knows the price I pay for getting jobs done’ (Jason, L92 – L94). For Jason, headaches were a consequence of his psychological dysfunction in how he approached his work, which stemmed from his low self-esteem at work.

For some participants, such as Barbara, patterns of psychological dysfunction (‘overthinking’) impacted behavioural functions (‘sleep’), which triggered ETTH:

I can literally be falling asleep, put my head on the pillow, and I’m contemplating the world. I just think... overthink things, I just overthink everything... Something will pop into my brain, that’s when I get the headaches the next day’ (Barbara, L737 – L742).

This alluded to how Barbara’s overthinking impacted on the care of the self, which, as with Jason, stemmed from her low self-esteem.

For Jason and Barbara, their approach to functioning at work was approached with psychological (dys)functioning, which increased ETTH. This I captured into the subordinate theme ‘the relationship between functioning and psychological (dys)functioning’.

The relationship between functioning and emotional (dys)functioning. For Angela, her headaches represented ‘bottled emotions’, which her public self could not express in relation to being honest about the stress she experienced as a mother, professional, and wife through the eyes of others, which were culturally reinforced and further exacerbated the self-isolation of the emotional self, as depicted below:

When I’m in pain, I can’t cry with my partner... he’s not keen to see me crying. At work, if someone hurts me, it’s not socially accepted, so I

cannot express myself. Instead, I may end up bottling it inside and feel tension in my head, but that's what I must do as a professional, wife, and mother (Angela, L161 – L182).

This shows how Angela's public self could not express her true feelings, which led to feeling isolated and not being authentic to her true emotional self within her relationship. Instead, she 'bottled emotions', which increased ETTH ('tension in my head'). This also alluded to low self-esteem and how her public self (in a relationship) was void of emotion, which was instead dealt with her private self (represented by ETTH).

Natasha voiced how she used to self-blame for having headaches: 'I try to prevent this headache from annoying me because I used to get really irritated with me having a headache. I used to be angry with me for having a headache, which made it worse' (Natasha, L409 – L415). She then went on to discuss how having ETTH was her own fault, which was associated with shame and led to self-suffering and self-punishment:

I'd say to myself, 'It's your own fault that you've got the headache... you shouldn't have done that or this... you shouldn't have done all of that studying... look what you've done now by eating that chocolate... you're suffering now'; the interesting thing [is], I used to say that 'You now must suffer in silence' (Natasha, L421 - L435).

For Natasha, ETTH became her secret: 'Because they are my fault, I'd sort them myself; I'd never tell anyone about how they were affecting me' (Natasha, L441 – L443). For Natasha, this meant isolation of the self.

This theme shows how Angela and Natasha's public selves were unable to express emotions and the private self was left to deal with emotions and headaches in

self-isolation. This was captured in the theme of ‘the relationship between functioning and emotional (dys)functioning’.

The relationship between functioning and behavioural (dys)functioning.

It comes on when I’ve pushed and pushed. It’s my body saying, ‘You can’t carry on like this...’ I feel sick and ill and need to go home and sleep it off, but this is usually after I have finished my mad schedule.

Towards the end, I’m paying the price where it’s so difficult to focus, and I can’t do anything, and my head is exploding (Lina, L106 – L125).

Lina’s functioning at work was associated with patterns of behavioural dysfunction – ‘mad schedule’ and ‘I’ve pushed and pushed’ – which showed how Lina’s behavioural approach to work resulted in neglect of the self. In the same sense, when she felt sick and ill, she would only go home when she had finished her ‘mad schedule’. For Lina, this meant that being unwell only signified her body physically stopping at the point of exhaustion. This also alludes to Lina’s low self-esteem at work, where she goes ‘above and beyond’ every day but lacks self-awareness of her body signals until her body physically stops her.

Even when resting, Lina became emotionally distressed as she felt ‘bad’ for not spending any time with her children as she had to rest. Lina alluded to not only suffering from ETTH because of long working days, but within the wider social context her children also suffered:

If I don’t need to be there with the kids, I explain to them that I’m in my room sleeping... as mummy is ill... ‘Only knock if it’s an emergency’. I feel bad because evenings and weekends are when I want to be with the kids, but I’m having to go to bed after a busy week at work (L147 – L152).

This impacted on Lina's self-worth as a mother. Interestingly, Lina described ETTH as being in a constant battle with her physical self, an analogy of being in a tug-of-war – 'Your body is fighting against you' – where she 'self-medicated' the self to carry on working until midnight. 'It's like your body fighting against you... you are exhausted' (Lina, L352 – L354).

When probed further, the participants in this study directed negative emotions toward themselves for losing this tug-of-war; in this way, participants described how they blamed themselves for being weak through continual use of critical self-dialogue, as illustrated by Lynn. 'I just get annoyed at myself ... not being able to keep on going' (Lynn, L421 – L422). This resulted in unexpected emotions at the consequences of pushing the self to function within life with ETTH, 'Thinking about the implications [of an accident whilst driving with a headache] can be frightening ... sad that I put myself in that position' (Lynn, L842 – L846).

All the participants had full-time jobs and families. Lina behaviourally functioned to meet the demands from work and family but this became dysfunctional when she pushed her body to the point of feeling ill and neglecting care of the self in needing therapeutic rest. 'My husband says, 'We're going out... just take two tablets'... I have my tablets... drink... get very sociable... but pay the price for it the next day' (Lina, L498 – L503). At another level, this shows Lina's low self-assertiveness and self-worth in being unable to put the self first. When probed further, Lina described the guilt she felt for working as a mother and wife (emotional dysfunctioning) where she 'had to pay this price', which alluded to punishment and neglect of the self. This again amplified a tug-of-war between wanting to function at work and home but adopting a dysfunctional behavioural approach where there was no energy left for Lina to care for the self. Headaches for Lina represented her physical body no longer being able to cope with her dysfunctional behavioural patterns, where she pushed her body to the limit.

In contrast, Jason was self-assertive in missing out on family engagements so that he could rest after a stressful week functioning at work. However, he also emulated being torn between needing therapeutic rest for the self and over-thinking how his family perceived him. ‘I like going down to see my family... I’d like to go down ... and them saying, ‘When are you gonna come and see us?’ ... I’m constantly saying, ‘I can’t now’ ... It’s embarrassing’ (Jason, L498 – L502). This also depicts that, on one hand, he needed the time for the self to rest but this was because of his dysfunctional approach to his work, which led the self being compromised in social interactions. This led to social isolation of the self.

The experience of Lina and Jason showed that they functioned in all spheres of life but this came at a price where they neglected the self and, instead, put the needs and demands of others before them. This converged as the subordinate theme ‘relationship between functioning and behavioural (dys)functioning’.

In summary, the participants functioned in all aspects of life, where they meet the demands and needs from work and family. The participants approached this with emotional, behavioural, and psychological patterns of dysfunctioning, which resulted in the neglect of the self and thereby increased ETTH. All participants narrated how psychological, emotional, and behavioural functioning was closely linked with dysfunctioning. The three subordinate themes converged into superordinate theme two, ‘the intricate (entangled) relationship between functioning and (dys)functioning’.

A Love-Hate Relationship with Health Professionals and Medication:

Superordinate Theme Three

The final theme across the interviews drew on the varied relationship participants had with the health care system and medication, which I captured in the subordinate themes of ‘healthy and helpful relationship’ and ‘unhelpful relationship’ with the health care system and medication:

I was wondering that my headaches had got stronger or something because it wasn't touching the sides... Once they took Syndol off the market, I tried to ... sort of move away from the medicine anyway' (Lynn, L672 – L674).

This illustrated Lynn's two-way relationship with medication, where she took medication to minimise ETTH (healthy) and acknowledged that she relied on medication, which was no longer effective (unhealthy). This has been presented as two subordinate themes below, which depict a love ('helpful and healthy') and hate ('unhealthy and unhelpful') relationship with health professionals and medication.

Unhealthy and unhelpful relationship with health professionals and medication.

If I wake up in the middle of the night with the stabbing head pain, I have a nice supply of painkillers by my bed ... I just pop a few pills and then go back to sleep (Barbara, L65 – L68).

For Barbara, her relationship with medication went beyond serving the function of reducing pain associated with ETTH and into a psychological function of providing a safety net ('I have a nice supply of painkillers') and exerting control over ETTH by having medication by her bed. Throughout the interview, Barbara made consistent references to 'popping pills', which illustrated her addictive and habitual use of medication. This shows how Barbara took medication even when she did not experience ETTH: 'I'll invariably pop some more pills later in the day to make sure that I don't have the start of a headache' (Barbara, L90 – L92). In addition, she also stated that if she had pain, she would 'take some tablets before coming home and pop some more when at home ... take a couple ... and that usually helps' (Barbara, L383 – L386). This also suggests neglect for the care of the holistic self and a lack of self-awareness regarding how other aspects of her life could be contributing to ETTH.

Later in the interview, she indicated how she got worked up if she could not find her medication, which further emphasised her habitual and addictive relationship with, and psychological dependency on, medication:

I do know that if I can't find the painkillers – and I did this a couple of days ago – I get worked up. I woke up, and they were all empty ... I went searching around the house and then felt happy and went back to sleep (Barbara, L535 – L538).

Like Barbara, Lina also described how medication served more than a function of reducing pain. For Lina, medication awarded her the feeling of being safe and in control when faced with the uncertain pattern of ETTH, where she kept medication with her always. 'I always carry them [tablets] ... in my handbag ... my bedroom ... If at night I need to take it [medication]... it's there; even if out at night, I've got a pack' (Lina, L227 – L233). This alluded to Lina's self-dependency on medication so that she could function without pain.

On the other hand, participants such as Rita narrated how not taking medication was a sense of accomplishment: 'I think taking medication is the easy way out, to be honest' (Rita, L246). This depicted how Rita would endure pain associated with ETTH, which alluded to the suffering of the self.

Natasha talked about her unhealthy relationship with the health care system, where she felt that she was not taken seriously by her General Practitioner (GP). Unlike Barbara, for Natasha, medication was not the answer, and she felt that she was not valued by the doctor:

In my twenties, I gave up on seeing doctors... They didn't listen. I felt 'it-ed' ... I was an object ... I was just, 'Oh, you're just a headache ... we only have a few minutes, so once we've listened to you, go away and just take the medication' (Natasha, L665 – L675).

Natasha went on to explain why she saw her GP to be unhelpful, which further impacted on how she saw her own headaches: ‘I didn’t feel valued or treated as an individual. It was almost like, “What are you moaning about? It’s only a headache.” I left and decided it was something I had to deal with myself’ (Natasha, L711 – L719). For Natasha, this meant her GP did not ‘value’ the self from a holistic perspective and the seriousness of ETTH was deflected by her GP within a wider social context. This was internalised by Natasha’s self as something she had to deal with herself, where earlier on in the interview she discussed how her public self did not disclose ETTH with others.

This theme demonstrates how participants such as Lina, Barbara, and Natasha had an unhealthy relationship with medication (i.e. habitual and addictive) and an unhelpful relationship with the GP (i.e. not feeling understood and feeling devalued), which were central to their experiences of managing ETTH and were captured in the theme of ‘unhealthy and unhelpful relationship with medication’.

Healthy and helpful relationship with health professionals and medication.

Participants also provided insight into how their relationships with their health professional and medication were healthy and helpful to them. For example, Barbara described how, initially, she was too scared to see her GP, fearing that they would confirm that she had a terminal illness: ‘I was too scared to get to the doctor in case they confirmed I had a stroke or tumour’ (Barbara, L281 – L282).

Barbara then went on to describe how she felt reassured by her GP, which reduced her headaches: ‘I thought I’d go and see a doctor, and when she said, “You are basically a stress head, you need to calm down,” my headaches started getting better’ (Barbara, L283 – L286). For Barbara, her GP provided reassurance to the self. She also found that her GP provided useful advice rather than just medication: ‘She said, “You need to learn to calm down, try yoga, and have a massage.” She was really

understanding, and did not send me off with a prescription, like other doctors' (Barbara, L287 – L289). For Barbara, this meant that it was important that her GP understood the care of the self holistically rather than being reduced to pain and medication as an answer. This also alluded to the need to seek self-reassurance.

Participants also narrated how medication allowed them to function and live a full life, and how it was used in reducing headaches. Jason described how medication enabled him to better manage ETTH, thus allowing him to live a fuller life:

The medication helps to reduce the pain. This way, I can carry on with my life without it getting in the way too much. If it wasn't for the medication, I would not be able to work (Jason, L154 – L162).

For Jason, medication awarded control over his life and ETTH as well as the ability to carry on functioning without being dependent on medication. Later, Jason described the effectiveness of medication: 'I will take a few paracetamols, and it helps. It is rare that it does not help. I can feel that I can carry on with things' (Jason, L172 – L176). This shows how the self was able to function by taking medication when required, to reduce pain.

This theme shows how participants such as Barbara and Jason had a healthy relationship with their GP when reassurance was given and the holistic care of the self was addressed. They also had a healthy relationship with medication, which allowed them to carry on with their lives without being dependent on it. This converged into the theme of 'healthy and helpful relationship with medication and health professionals'.

The three superordinate and nine subordinate themes are further explored and discussed in Chapter Five.

Chapter Five

Discussion

Discussion

Analysis of the data resulted in three superordinate themes which were discussed as individual participant representations of each theme which were presented interpretatively in Chapter Four. These themes are discussed in relation to existing literature and their application to health psychology in this Chapter. Inevitably, the focus of the research on the 'lived experience' of participants resulted in complexity and a degree of overlap between themes. Accordingly, I will first discuss the phrase 'lived experience,' as this discussion is pertinent to each of the superordinate themes in this research.

Lived Experience

Using the principles of IPA (i.e., phenomenology, hermeneutics, and an idiographic approach), I explored the lived experience of ETTH as experienced and understood in the lifeworld of each participant (Smith et al., 2009). During the data analysis, I made efforts to remain reflexive and transparent in my interpretations, with the aim of staying as close as possible to each participant's interpretation of his or her experiences as lived and understood by them (Smith et al., 2009). This was facilitated by maintaining a reflective journal and discussing my ideas with my supervisors. While acknowledging the challenge of clustering the rich experience of the participants into superordinate and subordinate themes, the process of analysis resulted in four superordinate (though to some extent, overlapping) themes which I believed best captured the experiences of ETTH as understood and lived by the participants in this study (Smith et al., 2009). These themes: (1) the essential and versatile use of coping strategies in the experience of living with and managing ETTH, (2) the intricate (entangled) relationship between functioning and (dys)functioning, and (3) a love-hate relationship with health professionals and medication. Although the themes are discussed separately below, the overlap between themes is also acknowledged in

reflecting how ETTH is lived and experienced by the participants in this study (Smith et al., 2009). I will begin with superordinate theme (1).

The essential and versatile use of coping strategies in the experience of living with and managing ETTH: Superordinate Theme One.

In Chapter Four, it was found that coping strategies were essential to the lived experience and management of ETTH where participants were versatile in how they coped. This has been discussed below in relation to wider literature presented in Chapter Two.

The essential use of coping strategies when living with and managing ETTH.

The participants narrated their use of coping strategies as being essential to their experience of living with and managing ETTH. I went back to Folkman et al. (1986), who defined coping as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 572). Coping strategies refer to the specific efforts, both behavioural and cognitive, that people use to master, tolerate, reduce, or minimise stressful events (Affleck & Tennen, 1996; Roth & Cohen, 1986). Using the categorisation developed by Compas, Orosion and Grant (1993), participants made use of both adaptive and maladaptive coping strategies. Adaptive strategies act to reduce stress and promote long-term benefits whereas maladaptive coping strategies may reduce stress in the short-term but contribute to stress over time, which can affect physical and psychological health in the long-term. The World Health Organization (2006) define health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (p. 1). I found that the participant’s lived experience of how they managed ETTH consisted of the versatile use of both maladaptive and adaptive coping strategies, which further impacted on their health and well-being.

Versatile use of coping strategies which are both maladaptive and adaptive for the individual's health and well-being. The participants described various coping strategies they used as part of their lived experience of managing ETTH, which depended on: a) the situation, b) individuals or groups they were relating to, and c) levels of stress and control. The participants versatile use of coping strategies which I depicted on a continuum (see appendix 0) sheds a different light on the studies assessed in Chapter Two, which implied instead, that participants adopted a fixed style of coping (e.g. approach/active or avoidance/passive coping) that remained constant across all situations (Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006; Peters et al., 2005; Ramsey et al., 2012; Rollnik et al., 2001; Rutberg & Öhrling, 2012; Slettbakk et al., 2006; Wittrock & Myers, 1998). Studies show that flexibility in the strategies used to cope with chronic conditions and pain, are associated with a reduction in symptoms of anxiety and depression and in turn become an adaptive way of coping (Compas et al., 2006; Dufton, Dunn, Slosky & Compas, 2011; Kashdan & Rottenberg, 2010; Roth & Cohen, 1986).

It was interesting to hear the participants described how they would not talk to others about their experience of ETTH in order to function at work (Leiper et al., 2006; Moloney et al., 2006; Ramsey et al., 2012; Rutberg & Öhrling, 2012; Ruiz de Velasco et al., 2003) and in social settings (i.e., with family and friends) (Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006; Peters et al., 2005). For some, this may not be an optimal coping strategy as the participants described how this left them feeling isolated where they hid their symptoms of ETTH from work colleagues, friends, and family by putting on a pretence (Rutberg & Öhrling, 2012). As presented in Chapter Four, participants inferred a range of fears of opening to others regarding their ETTH which ranged from being doubted by others that they were unwell, having their performance or absence from work questioned, being judged as incompetent or lazy and

not fitting or being an interesting topic for discussion. These accounts further results of previous research highlighting the belief that it was better not to discuss symptoms with others (Leiper et al., 2006; Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhring, 2012).

What I found particularly illuminating was the fact that participants reflected on how not talking to others about ETTH showed strength, whereas talking about ETTH was a sign of weakness associated with descriptions of shame (Rutberg & Öhring, 2012). This finding resonates with studies that have looked at other health conditions, e.g., type 2 diabetes (Browne, Ventura, Mosely & Speight, 2013), chronic muscular pain (Werner, Isaksen & Malterud, 2004), chronic pain (Finerman & Bennett, 1995), lung cancer (Chapple, Ziebland & McPherson, 2004), and mental illness (Rusch, Todd, Bodenhausen, Olschewski & Corrigan, 2010), where individuals preferred not to disclose their health or mental illness due to feelings of shame and guilt about how people would react or perceive them.

At the same time, the participants also described how they disclosed ETTH with specific individuals who also experienced headaches (e.g., family members, friends, colleagues, and online support forums) which allowed them to normalise their experience of ETTH. This finding differs from the findings of Slettbakk et al. (2006), who found that similar experiences were shared only in formal social support group settings, yet partly consistent with the results of Belam et al. (2005), who found that people with migraines regularly confided in family and friends with the same condition. In this study, disclosure depended on whether or not the person or group were judged to have shared similar experiences. This has implications for Health Psychologists where they can develop online and local face-to-face support groups for individuals with ETTH. This would encourage individuals to talk about and share their experiences of ETTH as social support has been found to significantly enhance emotional and

psychological well-being in patients (Kim, Han, Shaw, Mctavish & Gustafson, 2010). Further, Health Psychologists should embed social support strategies when supporting individuals with ETTH.

Many participants reflected on lack of control they experienced over the irregular pattern of ETTH, which usually occurred during their early experiences of ETTH or when in situations when they were unable to put themselves first. This builds on studies looking at migraine where a similar battle was also experienced (Moloney et al., 2006; Ramsey, 2012). The findings from this study show how participants engaged in critical self-dialogue and self-blame which were maladaptive to the participants' psychological and emotional well-being. This adds knowledge to the studies reviewed in Chapter Two in which, individuals also discussed a loss of control (Belam et al., 2005; Helving & Minick, 2013; Leiper et al., 2006; Meyer, 2012; Moloney et al., 2006; Rutberg & Öhring, 2012; Slettbakk et al., 2006). Despite this tendency, some participants also described experiences where they did exert control over ETTH, its irregular nature.

This was achieved by stepping away, engaging in positive self-dialogue which was associated with participants who had a longer history of ETTH. It seems that over time they had learned, through their experiences that there was no gain in becoming stressed in situations over which they were unable to exert control. The participants associated this with increased self-efficacy.

However, these coping strategies (i.e., stepping back, self-nurturing, and positive self-dialogue) were not used effectively when their attention moved away from themselves to focus on external stressors. This finding is different from previous research in which participants were shown to consistently adopt an active or passive coping style in response to a range of situations (Belam et al., 2005; Compass et al.,

2001; Leiper et al., 2006; Peters et al., 2005; Rollnik et al., 2001; Wittrock & Myers, 1998).

The findings from this study showed that coping with stressful situations or ETTH did not evoke a fixed, characteristic coping style but rather a versatile use of maladaptive or adaptive coping strategies in responding to the triggers of ETTH and to the stressors around them. This finding is of interest to me, as it is akin to the work of CBT, which aims to raise awareness of the self and control in stressful situations (Sutton, 2016). This has implications for Health Psychologists who should focus on coping strategies which have worked for the individuals in reducing ETTH and apply these to situations where pain increases. Further, Health Psychologists can put together an information guide where individuals can learn from others experiences in coping strategies which have worked for them in reducing the negative impact of ETTH. This had been successful in patients with migraine which received a web-based informational intervention which led to an increase in self-efficacy to perform self-management activities, symptom management and coping (Bromberg et al., 2011).

It was thought-provoking to hear how the participants coped with the frequency of ETTH by constantly being aware of the triggers which was associated with having control and an increase in self-efficacy. This concurs with previous studies (Meyer, 2002; Moloney et al., 2006; Ramsey, 2012; Rutberg et al., 2013; Rutberg & Öhrling, 2012; Slettbakk et al., 2006; Wöber et al., 2006). In previous research, studies alluded to a group of individuals who were aware of the triggers of their headaches (Meyer, 2002; Moloney et al., 2006; Ramsey, 2012; Rutberg et al., 2013; Rutberg & Öhrling, 2012; Slettbakk et al., 2006; Wöber et al, 2006) but not to the challenges faced in trying to avoid triggers which were revealed in this study. This finding interested me, as the link between intentions and being aware of triggers did not necessarily convert into behaviours across all situations when other factors, such as stress, were encountered.

This is reflective of processes outlined in the transactional model of stress and coping (Lazarus and Folkman, 1984) and the theory of planned behaviour (Ajzen, 1991). In turn, Health Psychologists should apply these models to individuals with ETTH.

Further they should focus on how individuals relate to stressors which act as obstacles in carrying out health behaviours which decrease ETTH.

Participants accessed various types of information to identify the triggers and learn about how they could more effectively manage ETTH by accessing support from friends, online social support forums and third wave therapies (mindfulness). This helped to affirm feelings and experiences of ETTH and added to their repertoire of adaptive coping strategies where they focused on nurturing the self. However, the participants also reflected on how their strategy of trying these new ideas was, at times, short-lived when living a stressful and busy life where the self became neglected.

While some of the studies in the review alluded to health-seeking behaviours among individuals with migraines (Belam et al., 2005; Leiper et al., 2006; Peters et al., 2005; Moloney et al., 2006), none discussed the information accessed online or the interest that individuals had in third-wave therapies. This resonates with my systematic review, where I found that relaxation therapies, including third-wave therapies, reduced the frequency of headaches and stress in individuals with TTH/migraine (systematic review: Annex 1). This has implications for Health Psychologists where CBT and third-wave interventions such as Mindfulness and Acceptance Commitment Therapy (ACT) which have been shown to be effective for individuals with chronic pain (McCracken and Vowles, 2014) are used and evaluated for individuals with ETTH.

Also, throughout the participants' reflections of their lived experience of managing ETTH, I observed self-care behaviours that were adopted to achieve self-regulation (balance).

The use of self-caring health behaviours to achieve self-regulation. The participants narrated the pivotal role self-caring health behaviours played throughout their lived experiences of managing ETTH which aimed to achieve self-regulation (physical, emotional, psychological, behavioural, and spiritual). Johnston et al. (2014) has defined self-care as “the care of oneself without medical, professional, or other assistance or oversight” (p. 4), which has been associated with positive health behaviours that promote health and prevent disease (Miller, Naimi, Brewer & Jones, 2007).

A pronounced finding was the participants’ engagement in self-care behaviours which involved self-awareness and management of triggers to ETTH. This is similar to the finding in the studies in the review where the participants had identified triggers which precipitated TTH/migraine (Constantinidies et al., 2015; Iliopoulos et al., 2015; Wang et al., 2013). Participants were found to balance triggers (e.g., sleep, tiredness, food, rest, alcohol, and dehydration) to minimising ETTH (Belam et al., 2005; Helvig & Minick, 2013; Leiper et al., 2006; Moloney et al., 2006; Slettbakk et al., 2006) and achieve balance (e.g., reducing stress and tiredness and staying hydrated) of mind and body (Belam et al., 2005; Helvig & Minick, 2013; Rutberg & Öhrling, 2012; Slettbakk et al., 2006). Like some of the studies in Chapter Two (Helvig & Minick, 2001; Ramsey, 2012), this also had a psychological impact, where the participants described how they felt in control of their lives and ETTH. However, the adoption of self-care behaviours was not consistent throughout the lived experiences of the participants.

In Chapter Four it was found that whilst all of the participants described having a stringent self-monitoring trigger process that proved to be successful in the management of ETTH (Meyer, 2002; Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhrling, 2012; Slettbakk et al., 2006; Wöber et al., 2006), they also noted an opposite approach where their intention of self-monitoring triggers did not convert into the

avoidance of the said triggers when faced with stress or when having to meet many responsibilities (Moloney et al., 2006). In this sense, the participants implicitly reflected on a paradox in which tension arose from intending to monitor triggers but being unable to sustain this when experiencing stress or not taking care of themselves. For example, the participants monitored their water intake to avoid being dehydrated (Slettbakk et al., 2006), but this was not sustained when feeling stressed or when engaged in meeting responsibilities. While studies in the review discussed the identification of triggers, only one study discussed the struggles faced by individuals when avoiding triggers (Moloney et al., 2006).

An interesting finding was that the participants reflected on how they learned to nurture themselves in order to self-regulate being stressed where they kept the focus on the self and not external stressors (Slettbakk et al., 2006). For example, going for a walk, take time out, have a relaxing bath, or engage in behaviours associated with having control over ETTH and their lives (Belam et al., 2005; Helvig & Minick, 2013; Leiper et al., 2006; Moloney et al., 2006; Rutberg & Öhring, 2012; Slettbakk et al., 2006). Conversely, all the participants described how they neglected themselves when dealing with stress with 'quick fixes,' which compromised self-caring, such as taking medication, drinking excessive amounts of coffee and/or alcohol, eating unhealthy foods, and smoking. These reflections indicate that the participants struggled in maintaining self-care behaviours to achieve self-regulation when faced with stress, which was not discussed in the reviewed studies. This has important implications for Health Psychologists who can support individuals in raising awareness of how stressors and other factors can result in the individual compromising on the care of the self. This can then be used as a resource from which strategies are put together which focus on health behaviours which prevent ETTH.

This finding depicted how individuals endeavoured to carry out self-caring health behaviours to achieve a balance and self-regulate but struggled when faced with demands placed on them which were not found in the studies reviewed in Chapter Two. Informing individuals with ETTH about these challenges would provide them with the reassurance that other individuals with ETTH also have similar struggles when adopting health behaviours to minimise ETTH. In addition, support for individuals with ETTH should include a holistic approach which embraces various aspects of the individual's life, such as the biopsychosocial-spiritual model (Sulmasy, 2002), an aspect not discussed in the reviewed studies.

Throughout the narratives of participants' defence mechanism were also used to manage life with ETTH.

The use of defence mechanisms as a way of coping. Participants described how they used a variety of defence mechanisms which were beneficial in the short-term but had an adverse impact when employed over a long period. Indeed, Carlson (2014) asserted that a defence mechanism begins by being protective and healthy for the individual, but when overused it can change to an unhealthy way of coping with pain. I analysed several types of defence mechanisms used interchangeably by the participants depending on the situation, experience of ETTH, and relationality with others.

Categorisation of defence mechanisms. Participants used a variety of defence mechanisms which is different to the studies I reviewed, where researchers discussed the use of denial and avoidance as umbrella terms (Holahan & Moos, 1987; Rollnik et al., 2001; Wittrock & Myers, 1998), possibly due to defence mechanisms not being the central focus of their studies.

The complex use of defence mechanisms. All the participants contemplated their refusal to accept ETTH as a helpful coping strategy, something the studies in the review described as avoidance (Belam et al., 2005; Peters et al., 2005; Rollnik et al., 2001;

Rutberg & Öhrling, 2012). This study showed how participants pushed ETTH to the back of their minds which concurs with Trevithick's (2011) explanation of denial, where information of events are rejected or blocked from awareness if considered threatening, frightening, or anxiety provoking. The participants described how they increasingly refused to accept ETTH as they were worried they had a serious/terminal illness, which prevented them from seeking help from a health professional, and which can be described as a (1a) maladaptive way of coping (Leiper et al., 2006; Rollnik et al., 2001; Wittrock & Myers, 1998).

This finding was in line with those from the reviewed studies, which suggested that avoidance/denial was a fixed way of coping (Leiper et al., 2006; Rollnik et al., 2001; Wittrock & Myers, 1998). However, I found that the participants' use of denial changed depending on their experience of ETTH and how they responded to situational stressors or responsibilities. Further, the participants substantiated the fact that they dipped in and out of using denial as a way of coping with ETTH, where they blocked things out of their minds so that they could get on with impending deadlines or important family events, which can initially be described as an (1b) adaptive coping strategy to get them through the day, but then became (1a) maladaptive when they reflected on how they self-medicated to get them through.

This finding was stimulating for me as a trainee Health Psychologist, as I felt that raising awareness of the use and implications of denial in different situations could support individuals in acknowledging ETTH as well as facilitating the use of health-seeking behaviours. Indeed, Nicholson (2010) suggests that it is important for psychologists to work with patients to replace minimising and avoidance approaches to coping with headache so that they can effectively identify and employ adaptive coping strategies for the effective management of headaches.

It was interesting to find that participants described how they changed the subject when their colleagues asked if they were unwell, also known as deflection, which is “a defensive act in which attention is diverted from an unpleasant thought or idea” (Corsini, 2002, p. 257); in this sense, humour is a type of deflection where the individual deals with emotional conflict or external stressors by emphasising the amusing or ironic aspects of the conflict or stressors (Trevithick, 2011).

It was noteworthy that seven of the participants did not want to talk about ETTH at work, so they used humour interchangeably with minimising ETTH. Minimisation is a defence mechanism explained as a type of deception, which is the opposite of exaggeration, where the individual downplays the significance of an event or emotion (denial coupled with rationalisation) (Guerrero, Anderson & Afifi, 2007). This partly accorded with some of the studies in the review, where individuals hid TTH/migraine at work (Leiper et al., 2016; Moloney et al., 2006; Ruiz de Velasco et al., 2003; Rutberg & Óhrling, 2012). This was of immense interest to me as a researcher, where participants reflected on their experiences of ETTH but did not refer to the term ETTH during the interview, instead referring to the term ‘headache.’

Furthermore, several participants reflected on how they made assumptions that other people would be uninterested in listening to them talk about ETTH, but this was never verbalised by anyone which I interpreted as projection. Rycroft (1972) explains projection as people attributing an intolerable, unacceptable, or unwanted thought, feeling, action, or attribute onto someone else or something else.

It was interesting that when compared with the defence mechanisms used by most of the participants, five of them narrated how they reassured themselves that everyone else also had headaches and pains and that it was normal to have ETTH. In this case, they were using rationalisation to cope with ETTH, which Colman (2009) explains as occurring when a false but reassuring or self-serving explanation is

contrived to explain behaviour arising from a repressed wish. Interestingly, some of the participants asked me to confirm if ETTH was normal, as they felt uncomfortable dealing with it. This was a moment of self-awareness, where they answered their own questions by saying that this was not good and that everyone lived with pain. I found that the participants had few opportunities to reflect on ETTH, which reinforced their continued use of defence mechanisms that became ingrained in their day-to-day coping and living with ETTH, resulting in a (1a) maladaptive coping strategy when used over a long period since it prevented participants from accepting ETTH. While the work I reviewed alludes to individuals coping with either the use of avoidance/denial or approach/acceptance (Belam et al., 2005; Lampl et al., 2016; Özdemir et al., 2014; Peters et al., 2005; Rutberg & Öhring, 2012), these studies took a fixed position. This could be because of their chosen research methodologies, which either involved using questionnaires or qualitative enquiry which did not fully explore the participant's lived experiences.

My study has shown that the use of defence mechanisms was an integral part of coping and living with ETTH, where participants interchangeably used different types of defence mechanisms, which were more complex and varied than simply denying or avoiding ETTH. This has important implications for Health Psychologists which as discussed above should use Mindfulness and ACT (McCraken and Vowles, 2014) as an intervention.

The intricate (entangled) relationship between functioning and (dys)functioning: Superordinate Theme Two. A continual theme throughout the participants' descriptions of their lived experiences of ETTH was how their need to function was intertwined with dysfunctional patterns of thinking (psychological), behaviour, and emotion as presented in Chapter Four. Indeed, functioning and dysfunctioning were narrated by individuals as being intertwined. I represented this

with the term ‘intricate,’ which is defined as “difficult to understand, obscure, complex, puzzling, entangled or involved” (Butterfield et al., 2003, p. 851). Preedy and Watson (2010) discuss how psychological functioning refers to individuals reaching goals within themselves or the external environment, which includes behaviour, emotion, social skills, and overall mental health (cognitions). In contrast, dysfunction has been defined as “any disturbance in function or failure to show characteristics or fulfil the purposes accepted as normal or beneficial” (Butterfield et al., 2003 p. 513).

A tug of war between functioning and (dys)functioning. A compelling finding throughout the participants’ descriptions of their lived experience of ETTH was how their day-to-day functioning was intrinsically linked to psychological dysfunction, emotional dysfunction, and behavioural dysfunction. This finding contrasts with that of the studies in the review, which concluded that participants struggled to function in life (Leiper et al., 2006; Moloney et al., 2006) but did not look at the deeper issues as to why this might be the case. Of those studies that did identify dysfunctional personality traits in individuals with CTTH (Aaseth et al., 2011) and ETTH (Cao et al., 2002), questionnaires only focused on personality dysfunction.

A noticeable finding was that the participants reflected on how they needed to function in life to meet with work, home, and social responsibilities, but how they found this a struggle when experiencing the physical impact of ETTH. This finding expands on those in the studies in Chapter Two, which looked at the adverse physical symptoms of migraine on functioning (Belam et al., 2005; Domingues et al., 2006; Helvig & Minick, 2013; Martin, 2000; Rutberg & Öhring, 2012).

Most the participants reflected on how their psychological and emotional dysfunctions were targeted at themselves for losing the tug-of-war between themselves and ETTH. Whilst the majority recalled their emotions of being angry and annoyed at themselves for not being able to function fully, the studies in Chapter Two concluded

that individuals directed their emotions towards migraine/TTH (Belam et al., 2005; Moloney et al., 2006; Rutberg & Öhrling, 2012; Wacogne et al., 2003). This intrigued me as the psychological and emotional characteristics associated with ETTH were not only behavioural manifestations (Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006; Peters et al., 2005; Ruiz de Velasco et al., 2003; Rutberg & Öhrling, 2012) but were deep rooted feelings which transformed every-day psychological and emotional 'manifestations' into dysfunctional psychological and emotional responses.

As presented in Chapter Four, unexpected emotions of behavioural dysfunctioning emerged during the interviews which appeared to provide a space in which participants could contemplate how their need to function in life was linked with dysfunctional psychological processes, including thoughts, emotions, and behaviours. This aroused my interest, as making a person aware of psychological, emotional, and behavioural dysfunction is akin to cognitive behavioural therapy principles, wherein dysfunctional cognition, behaviour, and emotions are addressed (Beck, 2011).

Furthermore, my systematic review found that individuals with TTH/migraine experienced a reduction in distress and headache severity after completing CBT-based interventions. This has important implications for Health Psychologists where addressing dysfunctionality are essential in helping individuals to self-manage ETTH. Further, Health Psychologists should carry out further work to explore the feasibility of constructing a questionnaire which assess dysfunctionality of thoughts, emotions and behaviours in individuals with ETTH.

While some of the studies in the review associated rest as a luxury and with feeling guilty (Belam et al., 2005; Moloney et al., 2006; Ramsey, 2012) which concurred with the findings from this study. It was also found participants saw rest as therapeutic for the self (Helvig & Minick, 2013; Slettbakk et al., 2006). This concurs

with Belam et al (2005) who also alluded rest as therapeutic but also associated with guilt.

Interestingly, while the participants reflected on the necessity of isolating themselves for rest/sleep, they narrated how they felt guilty when spending time away from family and/or cancelling social events to rest (Belam et al., 2005; Moloney et al., 2006; Ramsey, 2012), which I interpreted as an example of dysfunctional emotions. The participants illustrated how guilt was experienced because of having to function at work with ETTH and then having to rest, which detracted from family and social time (Ruiz de Velasco et al., 2003).

The participants described how functioning socially and at work while experiencing ETTH came at a price, where they described how they coped through self-medicating by eating, smoking, drinking, and the excessive use of medication (behavioural dysfunction). This contrasted with the studies which showed that individuals either socially withdrew or their social life was disrupted when experiencing TTH/migraine (Belam et al., 2005; Helvig & Minick, 2013; Moloney et al., 2006; Ramsey 2012; Rutberg et al., 2013) or they just pushed through work (Leiper et al., 2006; Moloney et al., 2006; Ramsey, 2012; Rutberg & Öhrling, 2012). The findings from this study could differ because of the focus of my analysis, which went deeper into different types of dysfunctional coping strategies and focused on behavioural and social dysfunction. Hence, while experiencing ETTH, the participants used dysfunctional behaviours to cope with functioning socially and at work.

A compelling finding was that participants described facing shame if others found out they were struggling to function and meet their responsibilities as a parent, employee, or partner. The participants dealt with this not by being honest with others but instead by denying, hiding things, or putting up a pretence so that they did not have

to face the shame for their inability to meet their responsibilities; this factor has been echoed in previous studies (e.g., Moloney et al., 2006; Rutberg & Öhrling, 2012).

The participants also reflected on how their personality traits impacted on how they functioned in life. For example, they described how their patterns of rigid thinking and setting high standards resulted in dysfunctional emotional and behavioural patterns. Similarly, previous literature reviewed in Chapter Two has shown that dysfunctional personality traits are higher in individuals with TTH/migraine than in healthy controls (Cathcart & Pritchard, 2008; Eskin et al., 2013; Huber & Henrich, 2003), where the participants' approach to functioning in life results in dysfunctional patterns of psychological processes, such as thoughts, emotions, and behaviours. They recalled how they overthought things (Helvig & Minick, 2013; Leiper et al., 2006; Peters et al., 2005; Rutberg & Öhrling, 2012), were continually worried (Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006; Peters et al., 2005; Ruiz de Velasco et al., 2003), over-analysed situations, and often greatly over-exaggerated the things that could happen to them, their loved ones, and the world around them. This is in line with the descriptions of psychological dysfunction in studies reviewed in Chapter Two in which an association between TTH/migraine and psychological distress was discussed (Adler & Adler, 1987; Baskin et al., 2006; Hatch et al., 1991; Lampl et al., 2016).

The participants used many distraction methods so that their mind would stop and they could get some sleep or rest even though this was short-lived. This finding is in contrast with those in studies which showed that TTH/migraine alone resulted in psychological dysfunction (Belam et al., 2005; Helvig & Minick, 2013; Leiper et al., 2006; Moloney et al., 2006); in this sense, findings from this study revealed that there is a two-way relationship between having to function but, in order to offset headaches, resorting to strategies contributing to psychological, emotional, and behavioural dysfunction as the result of living with ETTH. These findings may have differed from

previous research because of my line of enquiry and analysis, where I looked into the lifeworld of each participant and how they approached and lived their life rather than solely focusing on their experience of ETTH. Since participants in this study detailed how they adopted dysfunctional strategies throughout their accounts of their lived experiences. This finding is like that in the reviewed studies which associated dysfunctional personality traits with TTH/migraine (Cathcart & Pritchard, 2008; Eskin et al., 2013; Huber & Henrich, 2003).

Participants also discussed their relationship with medication and health professionals as being central to the management of living life with ETTH.

A love-hate relationship with health professionals and medication:

Superordinate Theme Three. I grouped the participants lived experience of their relationship with the healthcare system and medication as negative or positive. What stood out was that while individuals narrated both a negative and positive relationship with the healthcare system and medication, their experiences predominately resided in having a negative relationship with both. This finding is echoed in previous research which looked at TTH/migraine (Leiper et al., 2006; Meyer, 2002; Moloney et al., 2006; Peters et al., 2004; Rutberg & Öhring, 2012). Of note, Slettbakk et al. (2006) had omitted individuals' experiences with medication and healthcare from their study whilst this study brings to light these experiences in persons with ETTH.

It was interesting to see that most participants reflected on their positive relationship with medication as they described how medication allowed them to function in their daily life and gave them a degree of control over ETTH. This finding was similar to experiences of individuals with migraines (Moloney et al., 2006; Rutberg & Öhring, 2012). When probed further, the participants reflected on their positive experience of taking medication, where they referred to medication as a "miracle" which made it possible for them to live a full life (Moloney et al., 2006; Rutberg &

Öhrling, 2012). However, the participants also stated how their decision to take medication was not taken lightly as they had concerns about the side-effects and over-reliance on medication, thus alluding to a negative view of medication (Meyer, 2002; Moloney et al., 2006; Rutberg & Öhrling, 2012).

Participants also alluded to how not taking medication gave them a sense of accomplishment of enduring ETTH without the help of tablets (Wieser et al., 2012). However, they also described how they experienced hours of pain and tiredness when living with the pain associated with ETTH, which had a negative impact on them.

The participants considered being dependent on medication as failure or loss of control over ETTH, where medication was only taken as a last resort. I grouped this data as a negative relationship with medication. Interestingly, when medication was not taken, the participants described how they were more likely to try to identify triggers and consider the causes of ETTH rather than use medication. This approach is similar to the principles of mindfulness-based interventions, which support the individual in “paying attention in a particular way” (Kabat-Zinn, 1994, p. 4). Azam, Katz, Mohabir and Ritvo (2016) have shown that mindfulness practice can promote effective recovery after a stressful event for individuals with headache conditions. However, the participants’ negative views of medication and enduring ETTH without medication were short-lived when they needed to function and attend to their work and home responsibilities.

Moreover, the participants also voiced their liberal attitudes toward taking medication and referred to medication overuse (Jonsson et al., 2013). For example, participants reflected on how they would take pills when they sensed that ETTH was coming on, take medication in preparation for a long or stressful day, and experiment with various medications (Jonsson et al., 2013; Moloney et al., 2006). This negative relationship with medication gave rise to issues of medication dependency, which

Jonsson et al. (2013) identifies as occurring in headache-prone individuals who were physically and psychologically dependent on medication. In addition, the participants stated how they always had medication close at hand in case they unexpectedly experienced ETTH, something that was associated with the feeling of being safe and in control (Meyer, 2002; Moloney et al., 2006). This I interpreted as an unhealthy relationship with medication which served more than just the function of reducing pain. Paradoxically, the participants were concerned about the side-effects of taking medication and voiced concerns about the addictive nature of medication and being at risk of developing other health problems (Meyer, 2002; Moloney et al., 2006; Peters et al., 2004; Rutberg & Öhrling, 2012).

This exemplified a paradox faced by participants, and reflected in previous studies cited in Chapter Two, in which they voiced concerns about medication yet medication made it possible for them to function (Meyer, 2002; Moloney et al, 2006; Rutberg & Öhrling, 2012). This study showed how some participants abused and over-relied on medication to function. This has important implications for Health Psychologists who should raise awareness and explore possible issues around dependency and over-the-counter medication overuse (Frith, 2016). Further, collaboration between Health Psychologists and Pharmacist in developing informational leaflets which aim to support self-management of ETTH with a healthy relationship with medication.

An interesting finding was that the participants described the importance of seeing their GP in coping with and managing ETTH, where medication and reassurance were given. This positive relationship with the healthcare system was in line with the finding of studies on individuals with TTH/migraine (Moloney et al., 2006; Rutberg & Öhrling, 2012; Rutberg et al., 2013). At the same time, the participants also described how they initially delayed seeking support from their GP until they were left with no

alternative, and they felt a sense of relief when they visited their GP and were reassured that they did not have a serious illness (Leiper et al., 2006; Moloney et al., 2006).

This finding indicated that some participants initially had a negative relationship with the healthcare system, however eventually this became more positive. This finding contrasts with studies indicating that individuals either adopted a more enduring 'consulting' or 'non-consulting' style (Leiper et al., 2006; Moloney et al., 2006). At the same time, the participants also described a negative relationship with the healthcare system when the doctor did not take ETTH seriously (Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006).

Half of the participants in this study minimised ETTH by not talking about it when seeing their GP, describing it as an add-on to other illnesses, thus implying that the participants projected this thinking onto their GPs whereas they themselves did not take ETTH seriously when they visited their GP; this can be viewed as indicating a (5a) negative relationship with the healthcare system. This finding is distinct from that of other studies focusing on GPs minimising THH/migraine (Belam et al., 2005). The present study showed that this context included a two-way relationship, in which minimisation was employed by both the participants and health professionals.

An important outcome of these findings is that awareness is being raised through research and working with health professionals to raise the profile of ETTH and consider it as an illness. Further, the participants discussed accessing alternatives to medication, such as yoga, deep breathing, and mindfulness, but this was short-lived. This finding contrasts with the reviewed studies, where alternative therapies played a larger role in the experiences of individuals with TTH/migraine (Jensen & Roth, 2005; Peters et al., 2004). This finding differs from studies on CTTH/migraine in that individuals with ETTH may be less likely to access alternative therapies. Again, this has

implications for educating individuals with ETTH about the alternative therapies available to them.

Strengths of the Study

This study has several key strengths, the first one being the use of IPA. The principle of phenomenology during data collection enabled participants to talk freely about their experiences of ETTH without being guided by theoretical questions and a structured interview. The participants were experts in describing and comprehending these phenomena, informed by their lived experiences. This allowed me to understand, as closely as possible, the phenomena as lived by the participants and discover that they were versatile in their approaches to managing and living with ETTH. This contrasted with most the studies reviewed, which instead enquired about experiences using pre-defined theoretical categories (e.g., Eskin et al., 2013; Huber & Henrich, 2003) and portrayed individuals as adopting a fixed approach to coping (e.g., Belam et al., 2005; Leiper et al., 2006; Moloney et al., 2006).

Additionally, my phenomenological emphasis enabled me to focus exclusively on ETTH. At times, the participants discussed ETTH interchangeably with headache and migraine, and during the interviews it was decided to focus on ETTH. I also made use of supervision, which increased my awareness about considering ETTH interchangeably with other headache types/experiences. This contrasted with the studies reviewed, where headache types were discussed interchangeably and it was difficult to ascertain how the findings related to specific headache types.

A further strength of this study is that I adopted an idiographic approach throughout by using one-on-one interviews, where data was generated from 'individual' experiences. This is in contrast with a qualitative ETTH study (Slettbakk et al., 2006) focusing on 'shared' group experiences.

Moreover, I aimed to represent as many perspectives as possible without losing my idiographic approach. I included a sample of nine participants, which is at the upper end of the recommended sample size of four to nine for professional doctorates using IPA (Smith et al, 2009).

The final strength of this study is that its sample included a wide age range (18–65 years), different ethnicities, and both genders, thus ensuring its heterogeneity.

Limitations of the Study

There were several limitations to this study that I would address if I were to replicate it (Creswell, 2013).

The first limitation focuses on having a gender imbalance in this study, where eight out of the nine of participants were female and there was one male volunteer. It is purported that men and women experience headache and TTH differently (Celentano, Linet & Stewart, 1990; Rollnik et al., 2003) which I was unable to capture. Further studies should a) aim to investigate why males with ETTH are less likely to want their voices heard; b) recruit both men and women with ETTH equally so that the differences in experiences can be explored; and c) focus on the voices of males with ETTH who are an under-represented group in headache research (Robbins & Bernat, 2017).

A further limitation focuses on participants self-referring themselves with ETTH. Waldie (2015) suggests that symptoms of ETTH are often confused with mild migraine which could have impacted the outcomes of this study. In future studies, having individuals with ETTH referred by their GP would ensure that the voices of ETTH alone are captured.

Furthermore, participants were volunteers to this study which could have also impacted the outcomes of this study in the following ways. Dollinger and Leong (1993) suggest that research volunteers score highly on extraversion, openness and agreeability. This may have negated the voices of individuals with ETTH who are introverted and

score lower on agreeableness and openness which may have led to different experiences being captured. Future research, could ensure that volunteers are assessed on these traits or recruit individuals from GP referrals to counteract this.

An additional limitation was that participants were recruited from social networking sites are more likely to engage in health information seeking behaviours (Ellis, Mullan, Worsley & Pai, 2012). The findings in this study related to on-line informational support and interventions. Therefore, it would important to capture voices of individuals with ETTH who do not volunteer from social networking sites, to explore differences in how they manage ETTH.

A fifth limitation was that all participants in this study had full-time jobs where the importance of work featured as an essential part of the participants experiences of living with ETTH. It has been suggested that those who do not work tend to have poorer health than the working population (Langeland, 2009). Future studies should recruit non-working individuals with ETTH, so that the essential features of their experiences of living with and managing ETTH can be captured.

A further limitation to this study was the use of a professional transcriber. At the time, I believed that this would assist me in terms of time management; however, this eventually became a problem as I spent more time immersing myself in the data prior to analysing it. Smith et al. (2009) notes the necessary time needed to immerse oneself in the data; however, I discovered that there is no such thing as 'saving time' when working with IPA and needing to fully understand the lived world of participants (Smith et al., 2009).

The seventh limitation to this study was that I approached this study as a novice to qualitative methodology and IPA where my lack of confidence could have impacted data collection and analysis. Having gained new insights through my reflexive journey and explicit positioning throughout the study, I hope my further work and that of others

new to IPA will be approached with confidence from the insights documented in this study.

The final limitation relates to my training as a Health Psychologist which could have impacted on both the data analysis and interpretation. I strove to understand what it is to live with and manage ETTH, this was one version of the truth which was influenced by my training as a Health Psychologist. Future studies should involve collaborative work with multi-disciplinary research teams which could enrich the recommendation from this study to various health professionals who work with individuals with ETTH.

Recommendations

In considering the results of this study the following recommendations are made to inform the work of Health Psychologists as well as future research. Firstly, whilst IPA was useful in giving an insight into the experiences of living with and managing ETTH, these findings should now inform the scientific investigation of ETTH, using a survey design on a larger number of individuals (Boynton & Greenhalgh, 2004).

Further, in view of the key role emotions, thoughts and behaviours have in managing life with ETTH (successful or otherwise), Health Psychologists should use and evaluate CBT-based (Beck, 1960) and third wave (mindfulness and ACT) (McCracken and Vowles, 2014) interventions to promote effective self-management in individuals with ETTH. Indeed, CBT (Beck, 1960) has been shown to be effective in reducing the physical symptoms of chronic headache and migraines in adults (Harris, Loveman, Clegg, Easton & Berry, 2015) and mindfulness and ACT has been shown to be effective for individuals with chronic pain (McCracken and Vowles, 2014). These interventions have been effectively evaluated and have informed the effective self-management of a variety of chronic conditions (Eccleston, Morley & der Williams, 2013; Ehde, Dillworth, & Turner, 2014).

Additionally, Health Psychologists should further explore the versatile use of coping strategies to enhance the self-management of ETTH by using mixed methods (diaries, focus group, survey) (Katz, Vandermause, McPherson & Barbosa-Leiker, 2016) in exploring individual's resources used to manage this condition. Health Psychologists should use these findings to inform their own practice and the development of an information guide where patient's knowledge resources and experiences are used to support individuals who are struggling with the management of this condition. Indeed Peters, Abu-Saad, Vydelingum, Dowson and Murphy (2003) recommend headache patients should be used as a resource for effective self-management where they are active decision-makers in their self-management.

Moreover, this study informs Health Psychologists to further understand and address the challenges faced by individuals with ETTH in relation stressors which can act as a barrier in their intentions transcending into behaviours. Health Psychology and behavioural science could inform self-management interventions which help people cope with their ETTH by goal setting and implementation planning using Behaviour Change Theory (Michie et al., 2013).

Additionally, findings from this study encourage Health Psychologists to develop, pilot and facilitate online and face-to-face support groups, as participants in this study alluded to the importance of sharing similar experiences and accessing online resources. Research has shown that online support groups can reduce pain and stress (White & Dorman, 2001) and headache management packages for individuals with migraine/TTH should include methods of increasing social support (Huguet et al., 2014).

Furthermore, apps offering psychosocial support for headache sufferers via smartphones have been received well by individuals with migraine/TTH, allowing them to access a support network and to facilitate self-management remotely (Hardinge et al.,

2015). These apps have the potential to provide an environment in which individuals with ETTH can exchange similar experiences and coping strategies, and the opportunity to learn from each other's resources. Health Psychologists could support the design and evaluation of such packages.

And lastly, Health Psychologists are recommended to work collaboratively with Pharmacists in raising awareness of issues around medication overuse and dependency in individuals with ETTH where health-seeking behaviours and medication are further explored particularly as headache prone individuals are more likely to have an unhealthy relationship with over-the-counter medication (Frith, 2016).

Chapter Six

Conclusion

Conclusion

This study investigated the lived experiences and management of ETTH among nine participants with ETTH. The emergent finding was that living with ETTH meant facing many challenges when functioning in life while managing ETTH. This study calls into question the reputation of ETTH as a milder headache type (IHS, 2013); on the contrary, it is shown to be fraught with difficulties and complexities by the nine participants in this study.

First, participants were found to use a variety of coping strategies when living with and managing ETTH. While participants had the intention of using adaptive coping strategies, their efforts were sometimes compromised by the demands of daily functioning and stressors in life (Lazarus & Folkman, 1984). This finding built on those of previous quantitative and qualitative studies, that have implied a more fixed style of coping consistent across all situations in the context of migraine and TTH. The principles of cognitive behavioural therapy (CBT) may offer the potential for, individuals to become more aware of situations which evoke potentially maladaptive coping strategies, stressors, and dysfunctionality, whilst offering alternative methods to increase the effectiveness of their self-management strategies. It may also be empowering for individuals with ETTH to learn new adaptive coping strategies through peer support.

Further, this study has shown that participants identified many aspects in their life (e.g., stress, a busy life, and dysfunctional thinking, behaviours, and emotions) which prevented self-caring health behaviours (e.g., avoiding triggers to ETTH, mindfulness, and reducing stress) being adopted. This finding is different to previous studies which did not focus on the barriers preventing self-care behaviour. Health professionals could provide information on self-care behaviours beneficial to the management of ETTH and potential barriers to performing these.

Additionally, participants in this study found sharing similar experiences was beneficial in the management of ETTH. While this finding compliments previous qualitative research, which has evidenced the benefits of face-to-face social support networks in managing migraine/TTH, this study found participants reported benefits from the use of on-line support networks. Current on-line headache support networks do not cater for people with ETTH. Enhancing and promoting access to these on-line resources would allow access to a wider community of individuals with similar experiences, with potentially beneficial outcomes. Further, evaluating the effectiveness of on-line support groups for people with ETTH is highly recommended.

Moreover, this study has shown how participants used a complex set of defence mechanisms to manage ETTH. This finding, augmented previous research which has been restricted to the documentation of the use of denial and avoidance in managing TTH/migraine. This finding suggests that future research could further explore the complex use of defence mechanism in the management of ETTH by using a longitudinal study.

Finally, some participants had a love-hate relationship with medication and in a few cases, with their healthcare professionals. This important finding compliments previous research which pointed to the overuse of over-the-counter medication in headache prone individuals (Frith, 2016). This adds to the results of previous qualitative studies of people with ETTH which downplayed negative experiences with medication (Slettbakk, et al., 2006). Indeed, the unhealthy relationship with medication in some individuals with ETTH highlighted in this study is an urgent priority for further research.

ETTH had been defined as the milder headache type and the absence of migraine symptoms (IHS, 2013). However, this study has shown that individuals managing ETTH live a life fraught with complexities and difficulties. Exploring the

experiences of ETTH has brought the need for further research and support to the forefront so that those affected are not left in the dark to manage the impact of their condition.

At the beginning of this study, I selected IPA (Smith et al., 2009) to explore the participants' experiences of ETTH; this helped me understand the phenomenon as closely as possible without my analysis being unduly swayed by my pre-existing psychological health perspectives (Smith et al., 2009). There were, however, many challenges along the way that I had not anticipated and which impacted on my health. I found myself emotionally overwhelmed by the months of immersion in the data. The process of focussing on the accounts of others required me to suspend my own coping strategies. I required a period to re-group and complete the analysis. Despite these challenges, I would still recommend IPA to trainees in Health Psychology who wish to utilise an in-depth approach to the lived experiences of individuals. However, the data from IPA requires a significant time commitment to allow the unique perspectives of individuals to be heard. I would therefore urge trainees to begin their IPA studies as early as possible.

I am currently in a position where I can advise future trainees about the strengths and unanticipated challenges I faced, which will hopefully help some in their IPA journey. Most importantly, I have learned to accept support from, and talk to, supervisors and experts in qualitative research about ideas and thoughts; a book about IPA will not be sufficient to support the needs and/or the challenges you may face. Furthermore, I found that creative thinking is possible only by engaging in dialogue with others.

My ethical positioning has also changed in relation to the way I view the purpose of research. In this sense, conducting this study for my stage two training alone no longer feels sufficient. I have now begun disseminating my findings to colleagues

through research seminars, and I will continue to present these findings at conferences and via publications so that the perspectives of participants with ETTH can be heard, thus raising awareness about this condition (see Appendix Q for a dissemination of results from this study).

I conclude this thesis by asserting that individuals face many challenges throughout their lived experience of managing ETTH, not least because of the existing classification of the condition, which minimise the impacts of the condition (IHS, 2013). In this study, I have given a voice to the participants who live with ETTH, the “ugly duckling of headache disorders” (Folchini & Kowacs, 2015, p. 377), thus providing an insight into how challenging it is to live with and manage ETTH, in the hope that this research will inform support and intervention for this overlooked group.

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Appendix A
Reflexivity Chapter

Reflexivity Chapter

My journey began through a positivistic lens; it was an uncomfortable start with many obstacles ahead. Ignoring the obstacles was never going to work...but changing my lens did wonders for my work. Fog lifted, replaced by the sun...making it possible to finish my long run. (Rana-Rai, 2016).

Introduction

My journey began with an engrained positivistic attitude to research and academia. This story is how I overcame this attitude to engage with non-positivist qualitative methodology and complete my first Interpretative Phenomenological Analysis (IPA) study (Smith, Flowers, & Larkin, 2009). I explore what helped and hindered my transition. This leg of the journey in qualitative research ended with the embrace of subjectivity and putting "I" into research. This impacted both my perception of research and my academic career.

Feeling excited

“On the first part of my journey I was excited... oh the new qualitative thrill but the fog blinkered my transitioning shift.” (Rana-Rai, 2016). The systematic review (see Annex one) was akin to my positivistic orientation of analysing pre- and post-CBT intervention scores to understand TTH/migraine. This stems from my health and psychology training from the late 80s where I believed a quantitative orientation was the only way to carry out research which Howitt (2010) observes is how psychology tends to be done. These views also sat comfortably with my role as programme director of psychology, a role I had held for the last ten years and which encompassed a strong quantitative approach endorsed by academic colleagues and myself. But the SR left me feeling dissatisfied, as it did not get to the crux of the experiences felt with TTH/migraine, and I developed an inquisitive thirst for a more comprehensive methodology. I revisited excluded qualitative headache studies, finding them fascinating

as their approach allowed participants to talk about their lived experiences, which is akin to interpretative phenomenological research (Smith, et al., 2009).

Indeed, Biggerstaff and Thompson (2008) synthesise that "quantitative methods are not intended to take healthcare professionals to the heart of the patient's lived experience, they rightly focus on treatment outcomes, survival rates and clinical governance" (p. 3). I felt enthralled as a new world of qualitative methodology was introduced to me during my stage two health psychology training. I spoke to trainees and supervisors who were part of the rising ideology shift in health psychology. Hefferon and Gil-Rodriguez (2011) discusses this fashionable rise of IPA, evidenced by 294 empirical papers written between 1996 and 2008. This qualitative explosion had passed me by. The acceptance of qualitative methods and research may be viewed as a recent development in the long history of psychology (Howitt, 2010) and has grown rapidly where Biggerstaff (2012) evidences how the Qualitative Methods in Psychology (QMIP) section of the British Psychological Society is one of the largest growing sub-sections of psychology. My transition from a quantitative to qualitative research paradigm was underway; I felt I had a direction to move in and I was given permission to do so by the trainees and Health Psychologists around me.

I chose IPA (Smith, et al., 2009) for this study. With no "insider" knowledge, I set off on my journey with the belief that undertaking IPA research would be a relatively simple matter: reading IPA-framed psychology studies that examine health issues (i.e. Alexander & Clare, 2004; Chapman, 2002; Colton & Pistrang, 2004; Mendieta-Tan, Hubert-Williams, & Nicholls, 2012; Michie, Hendy, Smith, & Adshead, 2004; Rafique & Hunt, 2015; Walker, Holloway, & Sofaer, 1999); learning new skills (by attending a two-day IPA workshop); and reading and re-reading the IPA bible (Smith et al., 2009).

I was confident in performing the tasks ahead and could not wait to try out my new box of tricks. At the time, I thought I could write a qualitative research proposal for this study based on my recent reading. But I did not have the relevance of experience that Biggerstaff and Thompson (2008) rightly point out is the reflective driving force to help learn about using qualitative methodologies. In part, I had an over-simplified view that my transition from a positivistic to a constructivist paradigm was going to be a simple one; I quickly found that that this process could not be neatly defined as an epistemological walk from quantitative to qualitative. This assumption is depicted by Cooper, Glasser, Gomm, and Hammersely (2012) who state "it is hardly surprising that the various methodological ideas that now shape the work of social scientists no longer fall neatly into two inherently coherent, and differentiated positions if they ever did. Instead the shift is complex." (p. 6)

My excitement began to fade when I embarked upon this study and encountered work colleagues who were not interested in my conversations about narratives and prompts to tell me your story. Colleagues told me this was 'airy-fairy psychology' and they preferred just getting to the point. My professional identity was beginning to change and so was my approach to managing psychology at work. Where previously I held a scientific mode of thought, I began adopting a social sciences approach—words were becoming just as important as the numbers I worked with. This transformation also extended to how I saw the world. I began reading auto-biographies where the writers were the "experts", a view that aligns with IPA principles (Smith et al., 2009).

A mixed bag of emotions on my journey

"A journey which began with so much excitement changed to negative emotions and self-doubt...I sometimes wish I never took the first step... it was easier to have never ventured out on this journey." (Rana-Rai, 2016). The process of engaging with IPA research had an emotional impact. My initial feeling of excitement

was conjoined by unexpected feelings of being liberated, scared, helpless, overwhelmed and debilitated. The emotional impact led me to engage with articles that reflexively discussed the qualitative research process. For example, Ortlipp (2008) identified feelings of fear and desire as part of her experience of qualitative research process. Reeves (1994) discusses how self-awareness is only brought into conscious awareness when you learn by "doing in action". Ortlipp elaborates that reflective journal writing brings the unconscious into the conscious, creating transparency in the research process. Indeed, Ely, Anzul, Fredman, Garner, and McCormack Steinmertz (1991) describes the reflexive process as being integral to qualitative research, something that I began to further engage in.

Even though at the time I wanted to give up, I reflected, "for the first time ever I am at the centre of research where I am so involved with how this is going to all go". I was, as Burgess (1984) fittingly states, being consciously aware of "I" at the centre of knowledge produced in qualitative research. I approached data collection with the intention to follow the double hermeneutic cycle (Smith et al., 2009); I would be removed from the participant's experiences. I did not realise how much the "I" of the qualitative process would impact me.

I was excited to be leaving an objective world, where I once used pre-defined categories and theory to test hypotheses as an "outsider" to determine "one truth"; Howitt (2010) explains this perspective as an orientation where theoretical notions and concepts are confirmed. I felt liberated that I was now an "insider", exploring multiple truths depending on who was creating it (Smith et al, 2009). As Kanuha (2000) states, an "insider" is a researcher who conducts studies on groups he/she belongs to. I thought my experience of episodic tension-type headache (ETTH) defined me as an "insider". During data collection, it became clear that I over-simplified the distinction between an "insider" and "outsider". Witcher (2010) also suggests that researchers now recognise

that it is unrealistic to categorise oneself as an "insider" or "outsider". Far from being an "insider", I questioned myself when conducting interviews—"is this right, are the probes too intrusive, am I staying true to IPA and phenomenology?" This insecurity and confusion was further exacerbated when the participant's life worlds appeared different to mine. I even questioned if I had ETTH. Ironically, multiple realities/truths are at the crux of IPA itself (Smith et al., 2009). I was an "insider" when I was close to the participant's comprehension of their experiences, but I was an "outsider" to their experiences when I was reflexive in my approach (Smith et al., 2009). I ensured that I discussed my own experiences of ETTH with my supervisors so that I was aware of how my 'outsider' approach could deter me away from understating what it is like to experience ETTH.

I read more reflexive accounts of qualitative research (i.e., Witcher, 2010; Lambert, Jomeen, & McSherry, 2010; Mruck & Breuer, 2003) that reassured me. I also questioned my role as programme director; initiating a chain of events that concluded in me stepping down from my role to begin writing a master's in health psychology. According to Clarke and Braun (2013), a good qualitative researcher can step outside his/her cultural membership. However, this was a difficult time as my whole world, comprised of hard and fast rules, was changing.

I was reflexive during data collection, which Shaw (2010) and Smith et al (2009) states is central to IPA, where assumptions and experiences cannot be suspended and neither is it necessary. Instead, being reflexive and bringing into the conscious awareness my own experiences is essential in understanding how this could impact on understanding experiences of ETTH (Creswell, 2013). Part of this involved, not talking about my own experiences during the interview so that I could remain true to the principles of phenomenology but instead write down and discuss my ideas and thoughts with my supervisors, mentors and peers. This ensured that the participant was not

swayed by my own experiences and thoughts. I did not anticipate how debilitating it would be, to refrain from talking about my experiences when I felt ill during the data collection stage. I increased my journal writing and personal supervision, bringing into conscious awareness how not being able to talk about ETTH was impacting me. Now, I became aware of the process of counter-transference happening during the interviews where I carried emotional baggage associated with ETTH which were spoken about during the interviews.

Smith et al. (2009) describes data analysis as the second part of the hermeneutic cycle which did not emotionally impact me. However, in some moments I would slip back into thinking about theories and experiences identified in my literature review, as well as my own theories and experiences. As Allen-Collinson (2009) notes, being more critical and reflexive is central to qualitative research. My journal helped in this pursuit: "analysis data again today...a few times I have thought about how I have managed ETTH with medication and food...I need to carry on being aware of this so that I do not sway my themes coming from the participant's data." (Rana-Rai, 2016). The written reflections helped me to map my growing and changing understanding of my role as a researcher, interviewer and data interpreter.

During data interpretation, I felt overwhelmed with the amount of data I had to interpret, which according to Smith et al. (2009) is a long process. I remember feeling overwhelmed and at times frustrated for selecting an IPA framework: "I can't see the end... the more I do the longer it takes...." (Rana-Rai, 2016). It felt wrong to break up the participant's experiences, and I wrote: "will I even be able to get this all back together again when drawing a person with ETTH...I might not do justice to their voices." (Rana-Rai, 2016). My frustration increased when positivist colleagues would ask why I was taking so long to analyse my data. The analysis also detracted from my free time; I became so immersed with the data and for a period nothing else mattered.

Indeed, Tolich and Davidson (2003) make the distinction that quantitative analysis is quick and qualitative analysis is a longer process, due to its interpretive nature and having no quick formulation in place.

According to Smith and Osborn (2008), breaking up individual experiences is part of IPA data interpretation and it can be uncomfortable. For me, I sought reassurance from early 20th century Gestalt psychologists such as Koffka (as cited in Hedier, 1977) who states the whole is other than the sum of its parts. I began using this phrase with my students as an analogy for modular structures and assessment preparation. Ironically, I used the phrase to describe my journey where each step was a part that painted a bigger picture of the person with ETTH. This also evoked my creative side, which had dried up for so many years in my rule-driven world. I found that stepping away from the programme director role allowed me to explore my creativity, in that I was no longer being pulled in two directions—rules and formulas, and creativity and subjectivity. My excitement emerged again when the superordinate themes were finalised with their accompanying subordinate themes—"wow this all makes sense and has come together".

Coming towards the end of my journey, but realising it's only just begun: new challenges ahead

"My first turn on my journey is taken with a post-modernist lens... but the paved road did not help to complete this study, it was the traveller who was instrumental to this journey...but its only just begun." (Rana-Rai, 2016). As a novice to qualitative research, nothing prepared me for the many pitfalls and challenges I faced, but I learnt that "my" own resources were instrumental in completing this study. There were obstacles at each stage that were associated with negative emotions. For example: when learning skills in IPA I experienced confusion and self-doubt; suspending my own assumptions and pre-conceived ideas towards health psychology and ETTH during data

collection left me feeling debilitated; and the never-ending data-analysis stage left me feeling over-whelmed and at times regretful that I did not pick an "easier quick quantitative study for my doctoral studies". In every stage I could have given up, but learnt that I had the ability to recover and become resilient when obstacles became challenges.

Embarking on this journey meant leaving behind a positivistic orientation to research and work, which was my second skin. Taking a journey into post-modernist/constructivism research meant walking into the unknown where I was no longer an expert but had to learn new skills. Walking into the unknown was associated with feelings of shame, where I had to ask for help, got things wrong and felt stupid. What I learnt to do through my reflexive activities was, rather than allow shame to destroy me, turn this feeling into being "consciously incompetent". By doing this, I discovered an inquisitive thirst to learn from the experts: qualitative researchers, researchers who provided their reflexive experience of conducting qualitative research and participants with ETTH.

Throughout the stages of this study, I found that each task did not come to a quick end, which I tended to achieve with quantitative research and my work as an academic. For example, with positivistic research the data analysis section would take a week to complete, whereas in this study it took me four months. I got through the data analysis process with an attitude of self-determination and perseverance. In turn, I came to accept that each stage of this study deserved time for reflection and reflexive writing, which gives full justice to the voices of participants with ETTH.

I also learnt a great degree from my participants who were experts in their journeys of living with and managing ETTH. It was interesting how they identified triggers, that they avoided but also abused, which prompted the onset of ETTH. In my journal, I reflected on my own triggers and how I had the potential to abuse these

triggers when functioning. Instead, I became mindful and reflectively wrote about "I" in my journal; I had a voice in bringing many aspects of my life into my conscious awareness. I was the expert in my own journey as a novice qualitative researcher in health psychology.

When I commenced this study, I assumed the end of this journey would come when I wrote Chapter Five. During the Discussion Chapter I felt that IPA allowed my inner child to come out and be creative when painting "the person with ETTH". It felt that I was dancing with the birds and butterflies that now accompanied me on my journey (see picture at the end). I realised that this was not the end to my journey in qualitative research—I had only taken a turn along the path to complete this study.

Inevitably, there will be challenges ahead when I come to justify my use of IPA as a Health Psychologist trainee when defending this study by live voice (VIVA). In addition, my ethical awareness of research has changed where there will be no justice in interviewing participants for a completion of a doctorate. Instead, these voices must be heard, and I am sure I will face challenges when writing up this study for publication and presenting the material at conferences. I am also aware of the Stage One trainee Health Psychologists who are beginning their ventures into qualitative research. I endeavour to support them by not only talking about the potential pitfalls and obstacles ahead, but also how important they, as researchers, are instrumental in turning these obstacles into positive challenges.

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Appendix B

Choosing Interpretative Phenomenological Analysis (IPA) Chapter

Choosing Interpretative Phenomenological Analysis (IPA)

Introduction

This paper evidences my choice of interpretative phenomenological analysis (IPA) for qualitative inquiry (Smith, Flowers, & Larkin, 2009) as most suitable to explore the experiences of living with and managing episodic tension-type headache (ETTH).

Choosing Interpretative Phenomenological Analysis (IPA)

Choosing Qualitative Inquiry

Whilst the central purpose of qualitative research is to enrich understanding of the phenomenon in question, each approach has different theoretical and methodological approaches (Creswell, 2013). I selected a qualitative method for this study as this enabled me to gather rich accounts, enhance understanding of the phenomenon under investigation, and capture the voices of individuals that are rarely heard (Sofaer, 1999). In addition, Peters, Abu-Saad, Vydelingum and Murphy (2002) state that qualitative inquiry allows the researcher to gain an insight into the perspectives and behaviours of people with headache in their own words. This line of inquiry enabled me to address my curiosity of ETTH from the perspective of the individual, which arose from the systematic review (see Annex 1 for the full review). Qualitative methodology is also akin to social constructionism in that it rejects the idea that knowledge is objective reality (Launer, 1996), and instead supports the notion that knowledge is subjective and reality is dependent on who is constructing it (Pocock, 1995); an approach that sits with my epistemological positioning.

Choosing Qualitative Paradigm

Having decided that qualitative research was required, the next stage was to consider the qualitative paradigm/strategies that would help me to explore the *living experiences and management of ETTH*. Furthermore, I wanted to select a qualitative paradigm that would allow me to explore the multi-faceted experience of the individual

and how they interacted with the world around them. In turn, my philosophical positioning guided my choice of how pain is defined for this thesis, “pain is whatever the experiencing person says it is” (McCaffery, 1968, p.95). Utilising interpretative phenomenological analysis (IPA) allowed me to position myself with this definition throughout this study, where managing ETTH is what the individual says it is based on their experience, and where no one truth presides (Smith et al., 2009). The following section details why I chose IPA over competing qualitative paradigms.

IPA vs. discourse analysis (DA). Whilst these two paradigms sit within social constructivism, they still have “obvious and subtle positivistic premises” (Charmaz, 2000, p.510). Although I appreciate the role language plays in participants describing their experiences (Jorgensen & Phillips, 2002), I did not want to examine and analyse how individuals use language to describe experiences of ETTH, which is the aim of DA (Starks & Trinidad, 2007). Instead, I wanted to focus on how individuals ascribe meaning to the way in which they interact with the environment through gaining access to their inner world, which is akin to IPA (Smith et al., 2009). This methodology would allow me to explore the meanings that the participants ascribed to their experiences, and I the researcher would be able to engage with this interpretation to access the individual’s cognitive world, which is more akin to IPA than DA (Biggerstaff & Thompson, 2008).

IPA vs. grounded theory (GT). My intention was not to conceptualise and develop theory from the data, which is akin to GT (Glaser & Stratus, 1967, as cited in Samik-Ibrahim, 2000), rather I wanted to utilise the IPA approach of creating a rich description of the experience of living with and managing ETTH (Smith et al., 2009). I rejected GT as this would have limited my investigation to the social problems/situations that the individuals adapt to (Glaser & Strauss, 1967, as cited in Samik-Ibrahim, 2000). This in turn would have deterred me from exploring the

experiences particularly aspects that fall outside of social settings and interactions. I also found that having to ‘adapt’ would have restricted my exploration of experiences where individuals may have not been willing or unable to adapt, which would have moved me away from understanding the experience and situation as lived by the participant, which changes over time and is more in line with IPA (Smith et al., 2009). Furthermore, I did not want to develop a theory.

IPA vs. thematic analysis (TA). More a tool than a method (Boyatzis, 1998, as cited in Braun & Clarke, 2006), TA is guided by phenomenology during data collection where the primary goal is to identify, analyse and report patterns across participants (Braun & Clarke, 2006). This did not fit with my aim of identifying patterns within each participant and engaging with the everyday experiences of each participant’s life, with an idiographic focus on creating a biographical image of the participant’s lived experience. This is akin to IPA (Smith et al., 2009) whereas TA aims to create a more generalised view where pattern-based analysis is conducted (Clarke & Braun, 2013).

Choosing phenomenology

The philosophical principles of phenomenology naturally appealed to me as I wanted to explore how individuals made sense of their *living experiences and management of ETTH*. According to Rossman and Rallis (1998), phenomenology aims to study how people make sense of their lived experience, with Schwandt (2000) stating that phenomenology allows researchers to focus on the everyday, inter-subjective world as constituted from the participant’s perspective (Schwandt, 2000).

The choice of ‘interpretative’ phenomenology. The strand of phenomenology that appealed to me was IPA, as its principles aligned themselves to the aim of this study as well as my philosophical positioning (Smith et al., 2009). IPA is different to using phenomenology alone, where it would not have been possible to access the cognitive world of the individual through interpretation (Creswell, 2013). I wanted to

move beyond the participants' descriptions of their experiences to how both the research and I interpreted these experiences. According to Brocki and Wearden (2008), and Smith et al., 2009, individuals engage in self-interpreting activity when attributing meaning to their experiences, thereby suggesting that the understanding of a phenomenon is always open to interpretation. IPA supports this with clear guidance, where the individual interprets their experience during the data collection stage, with the researcher following this by interpreting their experience during analysis using the double hermeneutic approach (Smith et al., 2009). Smith and Osborn (2008) describe this as a two-stage interpretation process. Firstly, a double hermeneutic combines empathic hermeneutics with some questioning hermeneutics and is thus consistent with IPA's phenomenological origins. Aligned to this, some empathetic hermeneutics, where IPA details bringing into conscious awareness my own assumptions and pre-convinced ideas, which would allow me to get as close as possible to the way in which individuals experience the phenomena whilst being aware of my own assumptions and pre-conceived ideas through continual reflexivity and reflection (Smith et al., 2009) (see Appendix 1, where I chart my reflexive journey throughout this study). Secondly, IPA would allow me to interpret data from the perspective of a trainee Health Psychologist whilst remaining as close as possible to the participant's experience, thus allowing me to remain authentic to the experiences as described by the participant (Brocki & Weardon, 2006). Although Smith et al. (2009) claim that IPA acknowledges the participant as the expert of their experiences, they also recognise that there are no such thing as uninterrupted phenomena.

Conclusion

To sum up, my choice of IPA will allow me to focus on the experience of the phenomenon as lived and constructed by the individual, and interpret the data whilst remaining as close as possible to the individual's meaning of their described

experiences. This in turn will allow me to describe what it is like to experience and manage ETTH from the expert (the participant) whilst simultaneously being aware that there are multiple truths of a phenomenon rather than a true reality (Smith et al., 2009). In turn, IPA will allow the voices of individuals with ETTH to be heard, allowing me to access the inner world as lived by the participant. During data gathering and analysis, I will continue to reinforce the notion that there is no one truth and that everything is open to interpretation.

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Appendix C

Methodological Framework Chapter

Methodological Framework

Qualitative Research Design

I used a qualitative approach as the lived experiences of individuals are the subject of qualitative research methods (Al-Busaidi, 2008; Polkinghorne, 2005) which enabled me to provide a multidimensional understanding of ETTH which went beyond an everyday or common sense awareness (Curry, Nembhard, & Bradley, 2009; Kearney, 2001; Shepard, Jensen, Schmoll, Hack, & Gwyer, 1993). The primary aim for qualitative health researchers is to focus on how the individual makes sense of their world and experience of ETTH, as well as the meaning attributed to the phenomena of ETTH (Pietkiewicz & Smith, 2014). This is different to quantitative work looking at TTH and ETTH which has focused on post-intervention outcomes from psychological treatments which are reductionist and do not focus on subjective meaning of living with head pain (i.e. Kumar & Raje, 2014; Kikuchi, Yoshiuchi, Ando, & Yamamoto, 2015; Martin, et al., 2015; Martin et al., 2014).

The focus of qualitative research is on investigating personal experiences and their meanings in their natural and context-specific settings (Creswell, 2007). This study has been informed by a social constructed ontology where I see ETTH being complex, dynamic and socially constructed (Denzin & Lincoln, 2008). I see both the individual and myself, constructing meaning about ETTH within the context of a social world which is bounded with layers of meaning originating from the diversities in the contexts of human experiences and interpretations (Denzin & Lincoln, 2008).

Theoretical orientation of interpretative phenomenological analysis (IPA)

Interpretative phenomenological analysis is concerned with the detailed examination of human lived experience and it aims to conduct this examination in a way which as far as possible enables that experience to be expressed in its

own terms, rather than according to predefined category systems. (Smith, Flowers, & Larkin, 2009; p.32)

Interpretative phenomenological analysis is the approach I used for this qualitative study where I was concerned with exploring and understanding the lived experience of the phenomena of interest - ETTH (Smith, 2004). This orientation supported me to become engaged with a detailed examination of the individual's lifeworld and their experience of the phenomenon of ETTH, as well as engage with how individuals with ETTH made sense of their experiences and meanings that they attached to their experience of ETTH (Smith, 2004). IPA was introduced by Jonathan Smith in 1996 (Smith, 1996) and the method has since flourished in health psychology (Brocki & Wearden, 2006). Although IPA researchers continue to explore a diverse range of health conditions, there is some indication that research questions are becoming focused on particular health conditions (Williamson, Simpson, & Murray, 2008) which for this study I have focused on ETTH.

A growing body of IPA work has enabled the voices of under researched groups to be heard (Cassidy, Reynolds, Naylor, & De Souza, 2011), here I will be giving a voice to individuals with ETTH, another under researched group when compared with migraine (Slettbakk, Nilsen, & Malterud, 2006). The key theoretical perspectives of IPA are phenomenology, interpretation (hermeneutics) and idiographic (Smith 2004; Smith, 2007; Smith et al., 2009) which I followed.

Phenomenology

Phenomenology is both a philosophy and a family of research methods concerned with exploring and understanding human experience (Langdridge, 2007) which was introduced by Edmund Husserl as an eidetic method concerned with attending to the way things appear to individuals in their experience (Pietkiewicz & Smith, 2014). I have used these phenomenological methods to uncover the meaning of

the individual's experience of the phenomenon of ETTH through focusing on their concrete experiential account which has been grounded in everyday life (Langdridge, 2007) through their stories during face-to-face semi-structured interviews.

By basing this study on the principles of IPA, I have connected to the core principles of phenomenology through paying respectful attention to a person's direct experience and by encouraging participants to tell their own story in their own words (Smith et al., 2009). I position myself with the phenomenological understanding of the lived experience of ETTH which is not only individually situated and based on personal biographies but also intrinsically bound up and contingent upon relationships with others, coloured and shaped by social, historical and cultural perspectives (Eatough & Smith, 2008; Smith et al., 2009).

Hermeneutics

I believe that "without phenomenology, there would be nothing to interpret and without hermeneutics, the phenomenon would not be seen (Smith et al., 2009). Hermeneutics is the theory and practice of the interpretation of the meaning of text (Rennie, 1999) which I engaged in as a researcher to further attribute meaning to the experience of ETTH. According to the hermeneutic theorist Schleiermacher 1768-1834, as cited in Smith et al. (2009), a detailed interpretation of a text requires linguistic and psychological analysis which reveals the meaning of the text as well as un-intentional motivation of the original author (Moran, 2000). This resonated with myself, where meaning of ETTH went beyond the immediate claims made by the individual with ETTH, to attempting to reveal more about the individual with ETTH than they were aware of themselves (Smith et al., 2009).

Building on Husserl's work on phenomenology and Schleiermacher's work on hermeneutics (Smith et al., 2009), Heidegger fused his understanding of phenomenology with the theories of hermeneutics (Heidegger, Macquarrie, &

Robinson, 1962). I position myself with Heidegger where human existence is bound up with the world (people, things, knowledge, language, relationship, culture) where it was not possible to disconnect from indelible facets of the individual's life to reveal some fundamental truth about living with ETTH (Heidegger, Macquarrie, & Robinson, 1962; Larkin, Watts, & Clifton, 2006). Thus, the individuals with ETTH had their own unique way of living with ETTH, yet this was lived and experienced within a shared context (Cassidy et al., 2011). This in turn, influenced how the individual with ETTH interpreted their lived experience of the phenomena, and how I as the researcher interpreted the individual's account of ETTH (Smith et al., 2009).

Smith et al. (2009) concurs the Heideggerian perspective, where I tried to identify my basic understanding of ETTH and became further aware of my preconceptions during the interviews and analysis where the phenomena started to emerge (Heidegger, Macquarrie, & Robinson, 1962; Smith et al., 2009). I adopted a sensitive and responsive approach to data collection and analysis which allowed my preconceptions to be prodded and adjusted by the data (Larkin et al., 2006) which in turn resulted in a continual cycle of being in reflexive thought which underpinned by my care and concerns for the individual with ETTH. This results in me being aware that my lived experience is a way into the text, as well as a hindrance to understanding the text and that whilst I can identify some aspects of my preconceptions before the interviews, many emerged during the process of interpretation, as meaning emerged through the interpretive process (Moran, 2000; Smith et al., 2009).

Throughout this study, I engaged with interpretative activity to ascertain the meaning of living with ETTH for the individual (Pietkiewicz & Smith, 2014; Rennie, 1999; Smith & Osborn, 2008). I was aware that the individual with ETTH would be making sense and interpreting their experience and I would then be interpreting and making sense of their experience of the phenomena of ETTH, thus engaging in a double

hermeneutic approach (Smith & Osborn, 2008). At the same time, my interpretative effort will not ascertain a perfect understanding of the essence of the experience of ETTH as this will always remain hidden due to the interpretive activity that both myself and the individual living with ETTH has engaged within (Moran, 2000). I have not attempted to produce an objective or definitive account of ETTH as a phenomenon and can only claim to access a version of the experience as the individual makes sense of it through their narrative account (Smith & Osborn, 2008).

I have followed the hermeneutic circle as suggest by Moran (2000) of questioning, uncovering meaning, and further questioning which was driven by evolving hermeneutic questions.

The aim of the final analysed account was to offer a layered analysis of the phenomena of ETTH, by firstly where I provided a descriptive phenomenological level that conveyed an empathetic understanding of the experience of ETTH, and secondly by me further probing with a more critical analysis of the text which was based on the deeper interpretative work which I did (Eatough & Smith, 2008). This orientation, resonated with the classical hermeneutics of Schleiermacher 1998, as cited in Smith et al. (2009) and I applied this within a postmodern context of personal texts, which was co-constructed by individuals with ETTH and myself in the present day where meaning unfolded during construction as well as analysis of these texts (Cassidy et al., 2011).

Idiographic

The third theoretical orientation which IPA relies on is idiographic where I conducted in-depth analysis of single cases and examined individual perspectives of ETTH in their unique contexts (Pietkiewicz & Smith, 2014). Every single case study was explored before I made any general statements, so that I could focus on the rather than the universal (Smith, Harre, & Van Langenhove, 1995). Even when completing the final stage of analysis (cross-case), I remained faithful to the individual through

illustrating the lifeworld of participants who recounted their experiences of ETTH whilst also illustrating more general themes (Smith & Eatough, 2006).

IPA and this study

In summary, the aims of IPA – to provide a detailed examination of human lived experience, and the theoretical orientation - phenomenology, hermeneutics and an idiographic approach (Smith et al., 2009) informed the aims and design of this study. The aim of the study was to explore what it was like to live with ETTH and the management of head pain, which was ascertained from those living with the phenomena where I attained a rich detailed account of each individual story. Where possible, I was self-aware of my pre-conceived ideas throughout the data collection and analysis stage as any account of ETTH was subject to the interpretation by the individual with ETTH making sense of their experience, and my interpretation during data collection and analysis.

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Appendix D


Research Advert

Figure 1 Research Advert Poster



Research participants needed

Would you like the opportunity to share your experience of head pain?



I am looking for individuals who have experience of **tension type head pain** (feels like a tight band squeezed around the head) which can last between 30 minutes to several days, over an average of 1- 15 days each month (**episodic**)

Individuals with a diagnosis of migraine will not be able to participate

If you are interested, please contact: Devinder Rana-Rai
devinder.rana-rai@bcu.ac.uk

This study has been ethically approved by the University of the West of England

Appendix E

Inclusion/Exclusion Criteria

Inclusion criteria

People diagnosed with ETTH a minimum of 3 months before the start of the study

Adults (age 18 +)

People consent to take part in the research

English as a first or primary language (so that a continual dialogue is maintained and the researcher can support this dialogue with prompts).

Exclusion criteria

Individuals with a diagnosis of headache types which are not classed as ETTH

Individuals with dementia, psychosis or a diagnosis of psychiatric illness.

Appendix F**Participant demography**

Table 3

Participant ethnicity and ETTH history

Participant*	Gender	Age	Ethnicity	History of ETTH
Anne	F	30	British	No formal diagnosis, since early adulthood
Barbara	F	45	British	Formal diagnosis November 2013, since childhood
Lynn	F	35	Greek Cypriot	No formal diagnosis. Since undergraduate studies
Angela	F	38	British	Last 20 years, no diagnosis
Natasha	F	52	Irish	Since early adulthood, formal diagnosis 30s.
Rita	F	34	British – Asian	No formal diagnosis, since undergraduate studies
Jason	M	37	British	No formal diagnosis, since beginning work
Samantha	F	55	British	No formal diagnosis, since beginning work
Lina	F	41	British – Indian	Since childhood, diagnosis 4 years ago.

* *Pseudo names replace names of participants*

Appendix G

Semi-Structured Interview Schedule

Before we begin the interview, I want you to know that there is no right or wrong answer. I am here to listen to your experiences about ETTH. If at any time you would like us to take a break, or feel uncomfortable with what you are talking about, please do let me know and we can take a break and assess if you would like to carry on with the interview.

Question one

“I’m looking to explore the experiences of ETTH. The research is to discover how individuals live with and manage ETTH. I am wondering, if you could tell me about your experiences of living with ETTH?”

Probes/prompts: tell me how that makes you feel? What are you thinking at the time? What are you thinking now? How does this impact you/others? Tell me a bit more about that? How, why, when...

Non-verbal probes: silence (for reflection)/head nodding (to ensure I am attentively listening)

Question two

“Can you tell me about how you manage ETTH?”

Probes: tell me how that makes you feel? What are you thinking at the time? What are you thinking now? How does this impact you/others? Tell me a bit more about that? How, why, when...

Non-verbal probes: silence (for reflection)/head nodding (to ensure I am attentively listening).

Appendix H
Four Superordinate and 10 Subordinate Themes

Table 4 *Superordinate and subordinate themes across the nine participants*

Superordinate themes (and subordinate themes)	Anne	Barbara	Lynn	Angela	Natasha	Rita	Jason	Samantha	Lina	Total
1. Coping strategies	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Maladaptive	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Maladaptive	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Defence mechanisms	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
2. Functioning/(Dys)functioning	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Psychological	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Emotional	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Behavioural	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
3. Self-caring/self-reg.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Caring	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Self-regulation	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
4. Love-hate rel.										
proff/medication	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Unhealthy/unhelpful	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9
Healthy/helpful	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9/9

Appendix I: Transcript Analysis Exemplar (Anne)

			Original transcript	Exploratory comments
R1			<p>1 Okay so we're going to start the conversation now, there are no 2 right or wrong answers, I am interested in your experience of 3 episodic tension type headache. So, the study's looking at episodic 4 tension type head pain. Please tell me about your experience of 5 episodic tension type head pain.</p>	
P1	Mindfulness (L6-L7) Loss of control (L7-L9) Compartmentalisation (L10-L11) Loss of control (L12)	6 7 8 9 10 11 12	<p>Ow, erm, so I'm quite fairly familiar with head pain. Erm, I <u>observed for example last week that it felt like almost every day</u> <u>of last week or the week before, I'm not sure, that I had some kind</u> <u>of headache towards the end of the day.</u> Erm it's usually towards...behind the eyes, just above just behind the eyes, erm <u>and it's manageable in that I feel that I can still continue working,</u> erm <u>but it sort of yeah. I can't...I can't, entirely ignore it.</u></p>	<p>Monitoring occurrence (L6-L7)</p> <p>Awareness of headache frequency – hesitation not sure, does not know when headache is coming/going (L7-L9)</p> <p>Carry on working with headache (L10-L11)</p> <p>Attempts to ignore headache but cannot completely ignore it...when working (L12)</p>
R2		13	Okay.	
P2	Denial (L14)	14 15 16	<p>Erm I <u>didn't recognise, I don't recognise</u>, the, so when you in your <u>recruitment literature talk about this kind of band of pain. I don't</u> <u>necessarily recognise that, it's more towards the front of my head</u></p>	Not being able to recognise headache (L14)

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		17	I think. But usually towards one side. Erm is that the kind of thing you meant about physicality of implication?	Problems with recognising own headache/refusal to recognise headache (L15-L16)
R3		18	Yes, that's correct. How you experience your headache. There is not right or wrong answer, I am interested in your experience and how you experience headache.	
P3	Denial (L15-L16)	19	It was <u>last week</u> or the week before I'm not sure when I had it.	Hesitation, not sure when headache occurred (L22)
R4	Loss of control (L22)	20	Okay. So how does that make you feel? How did that headache make you feel last week or the week before, as you mentioned to me?	
P4	Doubt (L26-L28) Behavioural impact self-harm (L29) Minimisation (L28-L29)	21	It made me think okay...probably... I'm not entirely sure what I can say is the systematic source of why they occur. I have no idea actually. But I tend to think it's probably because <u>there's a lot going on</u> or <u>just back ground stress</u> . Or lack of Glucose or something and not eating at the right time. And it just made me think, erm, okay maybe I should monitor things a bit more...	Not sure of systematic cause (lacking awareness) L26-L28) Begins to identify a lot going on (L29) Stress referred to as 'just' background (L28-29)
R5		22	Okay.	
P5		23	...and yeah. Watch out that that doesn't keep happening.	
R6		24	I think it's of interest that you're mentioned a few things in terms of almost sort of symptom checks or possibly causative and...so	

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P6		<p>36 you talked about monitoring. Can you give me some examples of 37 how you've possibly monitored?</p> <p>38 Erm. It hasn't been systematic in any way. It's literally been me 39 going "oh, could this be because, erm, I ate lunch too late" or "I 40 was late in bed" or "I got up relatively early for me", or "has today 41 been a particularly stressful day"? So I remember for example, ok, 42 a classic example is, <u>my PhD viva having a blinding headache all</u> 43 <u>the way through that. Three hours...and I smoked at the time as</u> 44 <u>well and so I smoked a lot before that so I didn't know whether it</u> 45 <u>was particularly about nicotine or just the stress and I remember</u> 46 <u>being impressed that I actually still managed to get through the</u> 47 <u>viva and seemed to do pretty well on that with a headache. So I</u> 48 <u>feel like it doesn't, I can manage, to work. Erm, I don't tend to</u> 49 <u>medicate those kinds of headaches. I do if I'm pretty sure that I</u> 50 <u>know the cause like it's a hangover headache or I'm sick. But for</u> 51 <u>tension headaches I just tend to power through.</u></p>	
<p>self-regulatory (L39-41)</p> <p>Behavioural dysfunctioning (L42-L43)</p> <p>Use of smoking, self-medication (L43-L44)</p> <p>Awareness of triggers (L44-L54)</p> <p>Martyrdom (L46-L48)</p>			<p>Assessing balance by asking questions to oneself (L39-L41)</p> <p>Sitting a VIVA whilst enduring a headache = headache and VIVA (L42-43)</p> <p>Preparing for VIVA and smoking and smoking a lot before VIVA (L43)</p> <p>Questioning if headache resulted from different things - smoking or stress (L44-L45)</p> <p>Impressed with oneself (achievement?) – got through VIVA with a headache (L46-L48)</p>

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	Minimisation (L49-L51) Martyrdom (L51)			Does not medicate those kind of headaches, unless it is a hangover headache or sick (L49-L51) Experience pain from headache by carrying on without medication – power through – achievement? (L51)
R7		52	Tell me more about not medicating those kind of headaches?	
P7	Medication as a last resort (L53) Medication safety net (L55-56) Repression (L56)	53 54 55 56	<u>Unless it became particularly, particularly potent</u> I think. Also I don't trust my memory entirely so (laughter) there may be times when I've used, used...having said that <u>I've Ibuprofen in my room right now and I've clearly used it recently.</u>	Taking medication is headache is potent (L53) Surrounded by medication (L55-56) Establishing medication is around therefore must have taken medication (L56)
R8		57	Okay so you have medication next to you?	
P8	Medication as safety net (L58)	58	Yeah <u>yeah I have some next to my... in my office space.</u> Yeah.	Surrounded by medication (L58)
R9		59 60	It's interesting you mentioned, you mentioned, erm, viva, getting through viva.	
P9		61	...Mmm.	

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R10		62 ...and you know, you've talked about the VIVA and the lead up 63 to the VIVA as part of your experience when talking about 64 headache. I'm interesting hearing more about how this experience 65 made you feel?	
P10	Denial (L66) Loss of self-control (L69-L70) Negative emotions (L70)	66 Erm...mmm, I mean <u>it's all a bit of a blur</u> , the viva for example. 67 Erm bodily sensations. affecting my head area. Erm I don't know 68 if I can...I'm aware of anything else consistently anyway. Maybe 69 at the time. Erm how they make me feel. <u>Why did it have to come.</u> 70 <u>made me feel angry sometimes.</u>	Even though mentioned VIVA and headache, cannot express how this made one feel – a blur (L66) Questioning why headache had to come when preparing/sitting VIVA (L69-L70) Feeling of anger in relation to headache occurring during VIVA (L70)
R11		71 That's interesting. You say that made you feel angry when having 72 headache whilst preparing and erm.... taking your VIVA. Can you 73 tell me a bit more about how this made you feel, or what you were 74 thinking as the time as a result of this experience? You know when 75 going through the VIVA experience and having headache as you 76 mentioned?	
P11		77 Yeah...erm.	
R12		78 Okay.	
P12		79 What were you thinking?	

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R13		80	Mmm		
P13		81	Erm...		
R14		82 83	I mean what were you thinking at the time? When head pain comes on?		
P14	Isolation (L84)	84	I usually think it... I don't tend to mention it to people.		Not talk about headache to others (L84)
R15		85	Okay.		
P15		86	Erm		
R16		87	Why's that?		
P16	Defence mechanism (L88-90)	88 89 90	Erm, I don't know, that's part of managing it. I think it's probably part of an act of not acknowledging it. Erm, I usually acknowledge it after the affect.		In the moment does not acknowledge headache – as a way of managing but accepts this after headache has stopped (L88-L90)
R17		91	Afterwards?		
P17	Humour (L92-93)	92 93	Yeah, so. I had a. I had a headache at that point you didn't know but I was suffering (<i>laughter</i>).		Laughter when describing how one suffered but no one knew about it (L92)
R18		94 95 96 97 98	Okay so what makes you, because you mentioned self-acknowledgment...so what is it after the headache that then makes you acknowledge that? Is it the actually head pain that makes you acknowledge that you've had pain, you've endured pain.		
P18		99	Erm...so...		
R19		100 101	Take your time...it would be great if you could tell me a bit more about this.		

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P19	<p>Awareness of triggers (L104-L105)</p> <p>Self in control (L105)</p> <p>Loss of control (L106)</p> <p>Repression (L106-L107)</p>	<p>102 (Laughter). Is it not recognising it? Well I guess. I guess because</p> <p>103 it's quite...because it's so frequent. Probably because I have</p> <p>104 <u>caffeine addictions and stuff, so that...there are lots of reasons</u></p> <p>105 <u>why it might happen. It's just kind of background noise and</u></p> <p>106 <u>sometimes it ramps up. Erm...yeah. How do I acknowledge it to</u></p> <p>107 <u>myself though, I don't know...I don't know.</u></p>	<p>Identifying addictions such as caffeine and stuff as potential triggers (L104-105)</p> <p>Keep it in the background and carry on with life (L105)</p> <p>Whilst in the background. Sometimes headache ramps up – no longer in the background (L106)</p> <p>Is not aware of how headache is acknowledged to oneself (L106-L107)</p>
R20		<p>108 You don't know, well we'll come back to that. So, it's interesting</p> <p>109 you mentioned background noise. Can you tell me a bit more about</p> <p>110 background noise? That's an interesting way of describing your</p> <p>111 experience.</p>	
P20	<p>Mindfulness (L113-L114)</p> <p>Positive self-dialogue (L114)</p>	<p>112 Erm (pause 3 seconds). It's just...it kind of a familiar feeling, like</p> <p>113 <u>if I'm not concentrating on what, on my work or something...you</u></p> <p>114 <u>slip into thinking about yourself and what's going on. How am I?</u></p> <p>115 That's there that little bit of hmm (cough). Yeah I suppose it is a,</p> <p>116 <u>it's more of an ache. Just kind of a background fuzzy dull ache.</u></p>	<p>Focusing on the self when not focusing on work etc. (L113-L114)</p> <p>Checking in with oneself (L114)</p> <p>The use of 'just' background, fuzzy when describing headache (L116)</p>

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	Minimisation (L116)		
R21		117 So how does it impact you ...I mean headache...how does it impact 118 you, in terms of feelings and what you are thinking. Take your 119 time if you wish before answering. You know, how you live with 120 episodic tension type headache on a day-to-day basis and how you 121 deal with it.	
P21	Self in control (L123-L124)	122 Erm. I suppose at the end of the day it makes me feel some things 123 then <u>pleased with myself that I feel like I haven't let it get in the</u> 124 <u>way.</u> I have no counter reference point, I don't know.	Sense of achievement that headache had not got in the way (exert control over headache?) (L123-1124)
R22		125 Okay so it hasn't got in the way of ... (pause 3 seconds)	
P22	Motivational dysfunction (L126-L127)	126 I don't know, maybe it makes me give up on some things early than 127 <u>later,</u> then I would otherwise...maybe, I don't know, <u>I just tend to</u> 128 <u>distract myself with other things rather than...rather than think</u> 129 <u>about it too much I guess.</u>	Trying to get things done but has an impact where some things have to be given up earlier than anticipated (L126-L127)
R23		130 Tell me more about distracting yourself?	
P23	Deflection/humour (L131)	131 Work. <u>Work (laughter)</u>	Work as example of distraction is said with laughter (L131)
R24		132 Okay.	
P24	Critical self-dialogue	133 Well because, I guess maybe it's usually because <u>I'm in work</u> 134 <u>when it's happening.</u> So I should be continuing. Yeah and I do	At work, telling oneself that they 'should' carry on, despite experiencing headache (L133-L134)

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	(L133-L134) Mindful, Self-care/self-reg. (L134-L135) Positive self-dialogue (L136)	135 136	suspect that it's to do with sleep or caffeine or food and I usually think well okay, <u>make sure you get some time for dinner.</u>	Being aware of own behaviours which have caused headache – sleep, caffeine, food (L134-L135) Take time out for dinner. Taking time out for oneself – one says to themselves to make sure they take time out for dinner (L136)
R25		137 138 139 140 141	Okay. So, so, so, you've clearly identified what you would suspect as factors which are associated with head pain. Erm...and so do you tend to make it back on time for dinner? How, what kind of impact does that have when you are aware, of sort of caffeine intake and...	
P25	Spiritual self-care (L143-L144) Self-care emotional impact (L145-L146)	142 143 144 145 146	I suppose I assume that it's working or else I wouldn't keep doing it but it could just as easily be that it's the fact that <u>it's the end of the day and I'm relaxing a bit more.</u> Erm. Yeah, I guess I like to hope its things like that because <u>I have a bit more control over those than I do over anything else.</u> So...	Relaxation at the end of the day which has been possibly associated with reduced headache (L143-L144) Control over aspects of life – associated with things that work which reduce headache(L146-L146)

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R26		147 148 149	Mmm, so things that you hope, hoping, things that you can control. Yeah. What possibly could be true in fact of that may possibly not be in your control?	
P26	Loss of control work (L150-L151)	150 151	So things like stress or deadlines, things like that, <u>that can't really be dealt with.</u>	Cannot deal with above issues which are associated with headache (L150-L151)
R27		152 153 154 155 156	It's interesting to hear about your experience of how things...I mean aspects of your life, part of which you manage like relaxing which you have said you have control over which reduce headache and then other aspects of life which you don't have control which are associated with headache.	
P27		157	Hmm.	
R28		158 159	Okay. How does this impact on other aspects of your life, if it does?	
P28	Rationalisation (L164-L166)	160 161 162 163 164 165 166	Erm I don't know. Erm I would say.... erm.... erm...right okay. So tiredness per say definitely can do and also being hungry as well, so I do get angry. And that can make me pretty snappy...but I'd like to think and I may be wrong, that's different to the actual pain. Okay so <u>I wouldn't necessarily get snappy with family or friends or my partner because of the pain but I would do if I was hungry.</u> (laughs).	Impact on family/friends which is associated with hunger (not headache even though hunger above is associated with headache) (L164-L166)

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R29	167 168 169 170 171	Okay so, so, you're not less likely, like you say you wouldn't necessarily get snappy with family, friends or with your partner but you would when hungry. How would that impact? I mean what are you thinking, feeling at the time when with family and friends?	
P29	172 173 174	Mmm, sometimes do erm decide not to drink alcohol but only if we're in the house. <u>If we're outside I've already committed to that's happening...</u>	Sometimes do not drink alcohol (L172) Consequence of social commitments associated with not being able to eliminate/reduce alcohol (L173-L174)
R30	175	You're drinking alcohol. (Laughs).	
P30	176 177	<u>I'm drinking alcohol. And it helps sometimes, but then again I just think it's a distraction. Or just maybe relaxing.</u>	Drinking alcohol even though previously identified as a cause of headache, association distraction/relaxation(L176-L177)
R31	178 179 180 181 182	Yeah. It's interesting the words you keep on using of "relaxing" because you mention it in terms of the end of the day. And it possibly could be relaxation. I mean not necessarily in terms of eating a meal on time, so it's interesting, that you refer to drinking	

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		183	alcohol in social settings and then also reducing alcohol. How does this relate to your headache?	
P31		184	Hmhm. Hmhm.	
R32		185 186 187	I'm only saying back what I'm hearing from you. Is there anything else you'd like to tell me about sort of your, your, the impact of your headache?	
P32	Denial (L188)	188 189	Yeah I don't... I feel like it doesn't have too much of an impact but that's because...	Alcohol does not have much of an impact, even though previously discussed how alcohol impacts oneself (L188)
R33		190	Okay.	
P33	Denial (L191-L192)	191 192	(Sighs)... I haven't thought about it that much I guess, or at least I don't want to feel like it does.	Have not thought about impact of alcohol on headache, and does not want to feel like it does (L191-L192)
R34		193	Okay. Do you talk to anyone about your head pain?	
P34	Sharing similar experience – family (L194) Isolation (L194-L195)	194 195	Erm. Talk to sister sometimes who has migraines but <u>certainly not</u> at work because I don't see that as a <u>helpful thing</u> .	Talk to sister who has migraine (L194) Not talk about headache at work emphasised with 'certainly' not, associated with not being helpful (L194-195)
R35		196 197	Why wouldn't you see talking about your head pain as a helpful thing at work?	

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P35	<p>Projection (L198-L199)</p> <p>Medication as easy option (L200)</p> <p>Projection (L201-202)</p> <p>Catastrophizing (L202-L203)</p>	<p>198</p> <p>199</p> <p>200</p> <p>201</p> <p>202</p> <p>203</p>	<p>Because, there's, I wouldn't...I wouldn't get any benefit from moaning, I don't want to hear it so they don't. Do you want some painkillers?" I can sort that out myself and I don't want people to feel like. If I feel like I don't want people to approach me and I think that's because of my work, not because I'm an invalid in the corner or something. (laughter).</p>	<p>Making an assumption that others would not want to hear oneself moaning but does not cite any evidence of this happening (L198-L199)</p> <p>See others as offering medication for headache as an answer (L199-L200)</p> <p>View that medication is seen as an answer by others (L200)</p> <p>Assumption that headache may be confused with not being good at work (L201-L202)</p> <p>Associating headache with wanting to be perceived as an invalid in the corner (L202-L203)</p>
R36		<p>204</p> <p>205</p> <p>206</p> <p>207</p> <p>208</p>	<p>So it's almost, it's interesting when you've said, you know, people approaching you at work and you don't want them to think of you as an invalid because of your head pain. What gives you that impression that people have this perception of head pain at work in this way?</p>	
P36	<p>Impact functioning – shame (L209-L210)</p>	<p>209</p> <p>210</p> <p>211</p>	<p>I suppose it's probably not, well I guess yeah it's a sign of weakness, it's a physiological, I'm reacting, some part of me is struggling, with awful stress so you don't really wanna share that.</p>	<p>Assumption that others thing that headache is a sign of weakness at work (L209-L210)</p>

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	Self-blame (L210-L211) Isolated (L211)			Focus on one struggling with stress which follows physiological reaction which they are struggling with (L210-L211) Not want to share experience of headache (L211)
R37		212 213 214 215	So, so for you, your understanding of individual's perceptions would be its possibly a sign of weakness and you don't want that to come across within your working environment. Whichever working environment that would be.	
P37	Projection (L217-L218) Minimisation (L218-L219) Self-blame (L219-L220) Isolated (L222-L223)	216 217 218 219 220 221 222 223	I would... I would read that as...part of me would read that if someone else said that, <u>I would say okay you're clearly under stress and yeah it's just a way of signalling that. Like it's not as strong as if you were to be crying cause of stress but it's on the continuum of I'm not handling things very well and because it happens quite consistently...erm, once you've said it you'd have to keep saying it. (laughter). So you might as well always just deal with it.</u>	Seeing others with headache as a sign of experiencing stress (L217-L218) Reducing impact – comparing headache as not as bad as crying as a comparison (L218-L219) Headache identified as the self not handling things well (L219-L220) Deal with it by oneself rather than talking about headache with others (L222-L223)
R38		224 225	Okay and how does that make you feel? Because you're coming into work, you've obviously got a lot of deadlines and and things	

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		226	to meet but and then you've mentioned a sign of weakness. You don't want it to be, you assume it's being possibly perceived as a sign of weakness. Erm, how does that actually make you feel in terms of you do come into work, there are days where you will be enduring pain from what you've told me?	
P38	Martyrdom (L232-L233)	227 228 229 230 231 232 233 234	It kind of sounds a bit perverse but I probably erm frame that for myself then as the inverse, that it's a strength, that you can do that without acknowledging it to anyone else. That you, you know.	Associate not talking to others as a sign of strength (L232-L233)
R39		235 236	So it's a sign of strength then, getting through things without telling others. You got through it.	
P39		237	That's how I sell it to myself (laughter).	
R40		238 239 240 241	It is almost like you are saying that for you, it is a sign of strength when you don't acknowledge headache to others. Instead, you see it as an accomplishment to get through things which you see as a sign of strength.	
P40		242	Yeah.	
R41		243	But this is the very same pain we're talking about.	
P41		244	It's the same pain yeah.	
R42		245	Hmm.	
P42	Losing emotional control	246 247	Well, yeah, I think it is the, it's the opening up and acknowledging, yeah, that's where the weakness comes in.	Associating headache (accepting it) with weakness (L246-L247)

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	(L246-L247)			
R43		248	Okay.	
P43		249	To, probably.	
R44		250	Hmm. Okay. Interesting.	
P44		251	My head.	
R45		252	In your head. No, no, no it's really interesting, so we've slightly	
		253	touched upon how it impacts on your day-to-day functioning. Is	
		254	there anything else you wanted to tell me about how your head	
		255	pain impacts on your day-to-day...bearing in mind there's no right	
		256	or wrong answer, I'm interested in your experience and your	
		257	experience is unique to anyone else's. Erm, your impact on your	
		258	day-to-day functioning, so we've mentioned work. Are there any	
		259	other aspects possibly in work before we move to other aspects in	
		260	your life?	
P45	Behavioural dysfunction – physical withdrawal (L262-L264)	261	Errm...I don't think so. Nothing immediately pops into my head.	Contemplating then associated headache stopped/prevented one from taking part in exercise (L262-L264) Not having as many headaches associated with exercise (L265-L266)
		262	Erm...I'm just thinking I haven't been doing as much exercise	
		263	recently and I wonder, so I'm thinking in the past, has it stopped	
		264	me doing exercise, probably has, but at the same time I probably	
		265	didn't, maybe I didn't have them as much because I was doing	
		266	more exercise.	
	Behavioural self-			

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R46	care impact (L265-L266)		
P46	Spiritual self-care impact (L272) Catastrophizing (L273-275) Psychological self-care impact (L276) Catastrophizing (L277)	<p>267 So it's almost like a... ah that's interesting. So exercise...so</p> <p>268 there's possibly one of the things you do to manage your head</p> <p>269 pain but it's interesting you say as soon as that starts reducing you</p> <p>270 get the pain and then you don't feel like. Okay, so looking back</p> <p>271 how has exercise made you feel then?</p> <p>272 <u>It usually makes me feel good afterwards</u>. I haven't really</p> <p>273 associated it with pain before. I do remember one time I <u>decided</u></p> <p>274 <u>to go to the gym with a headache and texting someone to say, "just</u></p> <p>275 <u>in case I have an aneurism" on the treadmill or something...but I</u></p> <p>276 <u>think that actually did help me</u>, having exercised, <u>I didn't die</u> and</p> <p>277 erm, I think that becomes, or I assume, I can't remember very well.</p> <p>278</p>	<p>Taking part in exercise, afterwards feels good (L272)</p> <p>Linking going to the gym and having a headache with possibility of aneurism occurring, therefore text someone just in case an aneurism occurs – emotional/fear? (L273-L275)</p> <p>After working out at the gym, felt good, association with 'feeling good' (L276)</p> <p>Concluding after the gym that one did not die as a result of going to the gym and headache (L277)</p>
R47		<p>279 That sounds like there was something quite clearly there, in terms</p> <p>280 of you've had to text a friend, to say just in case.</p>	

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P47	Behavioural dysfunction (L281-L282)	281 282	Yeah I was like 'just in case'. Because <u>I knew I wanted to do some sport but I had there was headache and you never know.</u>	Two competing directions – want to work out and having a headache (L281-L282)
R48		283	Ok, that's interesting.	
P48		284	Hmhm.	
R49		285 286 287	Could you give me other examples possibly, where you felt like this in your life when experiencing episodic tension type headache?	
P49	Use of fluid, self-care (L289-L290) Self-regulatory (L291-L292)	288 289 290 291 292	Erm (pause 12 seconds). Yeah I mean there, that was probably the best example I can think of. Things like... <u>saying no to alcohol when I probably would have said yes in the past.</u> And that's me feeling like I should be, the other things is I feel like <u>I don't drink enough water generally.</u>	Saying no to alcohol over experience when compared to the past (L289-L290) 'Don't drink enough' water (L291-L292)
R50		293	Ah okay, tell me more about water.	
P50	Body process (L295-L296) Critical self-dialogue	294 295 296 297 298	Erm, that's such a basic thing. And I just don't do it. Erm and so if I've got a <u>slight headache I tend to use that as a signal maybe you should be drinking water, you should be rehydrating rather than dehydrating.</u> Erm but that's obviously sometimes gets in the way if everyone else is trying to actively let loose or whatever.	Association of headache as a signal of not enough water (L295-296)

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	(L296- L297) Impact spiritual self-harm (L297- L298)		Telling oneself that they <u>should</u> be rehydrating rather than dehydrating (L296-L297) Intention of drinking water but things getting in the way (L297-L298)
R51		299 Okay so it's really interesting that you've discussed how for you 300 it is important that you drink water but what I can hear is that you 301 also talk about how this can be difficult...you know difficult in 302 different situations or for you as you said, things get in the way. 303 At the same time, you also alluded to how you now say no to 304 alcohol whereas in the past this was not the case where you would 305 have had had alcohol. Very interesting. I would like to hear more 306 about this. Are there other experiences you can tell me about 307 where this has happened?	
P51	Self-blame (L308-L309) Critical self-dialogue	308 Yeah, it's literally me going, " <u>well you didn't have a glass of water</u> 309 <u>at three o'clock in the afternoon when there was no other</u> " and 310 " <u>now you've got some afterwards why you don't choose the right</u> 311 <u>one, for once</u> ".	Saying to one self that they didn't have a glass of water (L308-L309) Telling oneself to make the right choice (drink) for once (L310-L311)

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	(L310-L311)			
R52		312	And do you choose the right one? (laughs).	
P52	Mindfulness (L313-L314)	313 314	Depends on who I'm with. <u>When I'm with family I'll choose the right one.</u>	Choice of right drink (non-alcoholic?) more likely to have awareness when with family (L313-L314)
R53		315	Ah that's interesting...	
P53		316	Yeah, yeah.	
R54		317 318 319 320 321	...and why do you think you choose the right one when you're with your...isn't it interesting when you actually talk about your experience, so what is it about, so I, I would assume that you're talking about your family and you're choosing the right one as opposed to friends and partner possibly?	
P54	Awareness of triggers (L322) Self-care fluids (L322-L323)	322 323	Yeah, <u>with my partner as well, I'd probably choose the right one as well, I'd probably choose non-alcoholic.</u>	Right drink described as (non-alcoholic), awareness of trigger? (L322) With partner, select non-alcoholic drink (L322-L323)
R55		324 325 326	So what's the difference, so what has you stretching out for water when you are with your family and partner as oppose to friends?	

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P55		327	It's like...it's just strange yeah...when thinking about it	
R56		328	Tell me more why you think it is range?	
P56	Self-care health behaviour : fluids (L329-L334)	329 330 331 332 333 334 335 336	...it's probably different, probably different things. Different kinds of enjoyment and, erm, is it okay? Different kinds of enjoyment because <u>I know I can enjoy myself with my family and friends, erh, my family and partner just as much without alcohol, but it's probably also because I see them more often than some of my friends, see, they live further away, so then it's kind of more, erm, it doesn't happen very often, let's go for it. That's probably it.</u>	Family and friends see more often, associates this with seeing people often can enjoy company without alcohol (L329-L334)
R57		337 338 339 340 341 342	Okay, so the alcohol then comes into the mix and water takes a back drop then to that. Okay, so I can hear familiarity then possibly. With people and social settings. Okay. Anything else? Can you think back to a really bad, bad day of an episodic tension type head pain that you've had? Can you, can you, talk me through it in terms of your experience on that day.	
P57		343 344 345 346 347	(pause 3 seconds). A particular episode? Erm... hmm... I can't think of erm, I mean, I've got the examples that I gave you with the viva and stuff like that. That was many, many years ago now. (laughs) I don't remember this now but obviously that was a very special thing. Erm...I can give you kind of a generalised...	
R58		348	Yeah, or we could go back to the viva as an example?	

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P58		349 350 351 352	(pause 3 seconds). I'll see if I can remember from last week. Any particular. I'm bad at remembering anyway, one work day from another. Erm ...hmm (pause 4 seconds) I can't think of any specifics.	
R59		353 354	Okay. Okay, shall we go back to your... It's interesting that you can't think of a particular day but you did say they tend to yeah...	
P59	Rationalisation (L355)	355	<u>I just have a bad memory anyway for days.</u>	Finding it difficult to recall headache experiences, justification provided with poor memory (L355)
R60		356 357 358 359	Ok. Shall we go back to your viva because that's a really important time, time, in your life and do you want to talk about sort of the lead up to what was going on with you, in terms of the lead up to your viva.	
P60	Maladaptive coping: self-medication/smoking (L360-L363) Deflection/humour (L363)	360 361 362 363	Erm... how much do I remember? Erm, <u>with the viva I actually had a job in another country and had had to come back for it.</u> Erm... so there was a lot of catching up with people I hadn't seen for a bit then there <u>was a lot of smoking (laughter).</u> Erm...	Travelling back for VIVA, catching up with friends resulted in a lot of smoking (L360-L363) A lot of smoking (laughter) (L363)
R61		364 365	Okay. Was that smoking. Were you smoking within social settings when you were catching up with these people.	

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P61	Rationalisation (L367-L369)	366 367 368 369	Erm, yeah...erm, kind of... yeah not very many people, most of them didn't smoke, but I <u>was smoking with one friend, who smoked a lot and she was helping me prepare, to go into the room.</u> Erm (cough)...I wish I could give you more specifics.	Preparing for VIVA associated with smoking with a friend who smokes a lot (L367-L369)
R62		370 371 372 373 374 375 376	It's okay. No worries. So when you get this onset of headache during such an important event as viva. I'm just using viva as an example because that's what you're recalling in your experience. How does that actually make you feel because actually you've actually got a viva going on. Or you're preparing for a viva. It's one of the most important things, for, for... I suppose for you because you've mentioned it.	
P62		377	Yeah (laughter).	
R63		378 379	How are you feeling at the time when your experience, when that head pain starts?	
P63	Loss of self-control (L380-L381)	380 381	Erm I'm sure at some point I've thought this is the <u>last thing I need.</u>	Last thing one needs when preparing/sitting VIVA (L380-L381)
R64		382	Yeah.	
P64	Critical self-dialogue (L383)	383 384	<u>Why, why, today</u> but then at the same time I've thought <u>well obviously today (laughter).</u>	Questioning why one has headache on the day of VIVA (L383) States it is obvious headache happen today (day of VIVA) (L383-L384)

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R65	Negative emotion (L383-L384)	385 386	So it's, it's almost why today and then it's well it, well it was going to happen today.	
P65	Martyrdom (L388-L389)	387 388 389 390 391 392 393 394 395 396 397	This is part of the package. Erm because it means so much to me I guess because, the pressures on. Erm... yeah, <u>I remember being proud as well because after my viva the chair</u> of the session and one of the examiners said that I had been, seemed especially calm, especially compared to the general, yeah, calms a good word, erm, and I remember thinking yes! Despite the fact there I was, there was a lot of pain in my head and that was a particularly intense headache, that wasn't just a back ground one. Erm... yeah... and then <u>we went to the pub and then I drank a lot of alcohol</u> , and I don't remember it being an issue afterwards.	Proud of getting through VIVA (L388-L389) After stress of VIVA and headache, relax with alcohol (L395-L396)
R66		398	Okay. After, after, after you were socialising.	
P66		399	Mmm.	
R67		400 401 402	Ok, so it seems like it was such an important day, you had a lot to get through, a lot of appraisals there but you carry on with a smile. It's almost like going back to what you said again.	

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P67		403 404	Yeah. That's as much specifics as I think there I can give at that time.	
R68		405 406 407 408 409 410	It's okay, because it's what's important for you, that's what, that's what we're interested in looking at. Okay, so tell me a bit more, you've identified erm, a few things that you possibly would do to sort of cope, or manage, or whatever you want to say in terms of, of, of head pain. Can you tell me a bit about, a bit more about how you deal with headache?	
P68		411	Erm.	
R69		412	Tell me a bit about what you may do?	
P69	Self-regulate (L413)	413	<u>What I usually do is have a bit more coffee.</u>	Drink coffee to manage headache (L413)
R70		414	Coffee. Anything else?	
P70	Use of food self-care (L415) Self-regulation (L416) Defence mechanisms – (L416-L418)	415 416 417 418	<u>When I have bit more headache, I eat so I'm not hungry.</u> <u>Erm...makes me balance things and take notice if I need to change something, I'll probably start to rationalise it and say okay this is happening. Then continue as normal. (Laughs).</u>	Make sure not hungry by eating food (L415) Balance things and assess if in-take/things may need to be changed (L416) Contradiction rationalise, followed by acceptance then followed by carrying on as normal (<i>laughter</i>) (L416-L418)

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R71	419 420	Okay, so how does this relate to coffee in-take which you mentioned?	Okay, so how does this relate to coffee in-take which you mentioned?	
P71	421	Rigid thinking (L421)	<u>Need to eliminate it... well try to</u>	<u>Need to eliminate coffee in-take, followed by I will try (L421)</u>
R72	422		Okay and the food. What would you possibly do after that then?	
P72	423 424 425	Habitual use of taking medication (L423-L425)	Erm. Again depending on the time of day, when working, <u>when it's half past six to go home or something I'll probably take some Ibuprofen or something.</u>	End of the day at work will take medication (L423-L425)
R73	426		Okay.	
P73	427 428 429 430 431 432 433 434	Medication last resort (L427) Self-blame (emotional dysfunction) (L429-431) Medication as a last resort	I said probably. Like I said before <u>I try not to medicate it, unless it's... maybe I don't know, maybe it's some weird logic I have, I feel like if these are tension headaches these are because of my stress levels probably and whereas if I'm going to medicate something I do that when I know there is a source of pain; like a hangover or I don't know, I attribute it to something different, more medicatable or but again if it is pretty bad and then I'll take some Ibuprofen.</u>	Not take medication if tension headache (L427) Not relate tension headache to knowing source of pain other than own stress, therefore not medicate (L429-L431) If pain is medical or bad, then take medication (L432-L434)

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R74	(L432- L434)	435 436 437 438 439 440 441 442 443 444 445 446	So your, what I find interesting is that you're mentioning if it's almost... What I'm trying to distinguish between is: some pain which you can medicate and pain which you don't medicate so where does tension type head pain fall for you in terms of medicating? Because you mention other factors. You've mentioned exercise, lifestyle, you've mentioned dietary, liquid, okay, erm, going home and relaxation. You've mentioned all of those but I'm interested in what distinguishes between, where does, where does medication come on that list? To me, I mean, you've mentioned that right at the bottom but what distinguishes between the wish to medicate and the wish not to medicate? That's what I'm interested in.	
P74	Misuse of medication (L448-L449) Medication as a safety net (L449-L450)	447 448 449 450 451 452 453 454 455	Hmhm (pause 4 seconds) Erm...okay, that's a really good question...so certainly... <u>really obvious hangover type headaches</u> <u>I'll definitely medicate without thinking</u> and if I know <u>where the drugs are I'll take them immediately</u> along with lots of water. Erm <u>if it's in the week it's much less likely to be that kind of headache,</u> <u>certainly in the day time headaches, in the afternoon when do I decide if it's that kind of headache or not?</u> Erm... that's a good question. I don't know if I can give you a hard answer for what you're er...	Taking medication without thinking for hangover types of headache (L448-L449) Surrounded by medication associated with taking medication immediately (L449-L450) Identifying type of headache where one distinguishes weekend to weekday ones,

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	Mindfulness (L451-L453)				then talking through times of the day to assess type of headache (L451-L453)
R75		456 457 458 459	But what it sounds to me like, there's no such thing as an easy or a hard answer, that's not what I'm looking at. It's just your explaining to me your thinking process and how you're distinguishing and that's all I wanted to know a bit more about.		
P75		460	Hmhm.		
R76		461 462 463 464 465	I can hear you are looking at different times of days, days...different times of the week and then thinking about the type of headache which is interesting. You then relate this to thinking about taking medication or not.... does this, this relate to anything else that you may do?		
P76	Awareness of triggers (L466-L467) Awareness of fads (L467-L468)	466 467 468 469 470 471	Yeah... so if I'm pretty sure it's because of caffeine and water I won't medicate because I feel like that's... That's the thing I figured out. I test that theory first. Erm but then I yeah, clearly it's the case that sometimes I've taken Ibuprofen in work and I wonder, I too would like to know why I've decided to do that then, but I don't consistently do that.	Identifying caffeine and water as causes then won't take medication (L466-L467) Trying out theory first – things to eliminate/increase (L467-L468)	Medication taking at work (L469)

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	Self-medication, medication (L469)				Question why medication is taken at work (during this interview) (L470)
R77	Emotional impact self-care (L470)	472 473 474	<p>472 Hmm, why do you think you did that then? Took Ibuprofen at work when you don't, you've said you tend not to do, but you, you have Ibuprofen, you have that in your desk.</p> <p>473</p> <p>474</p>		
P77		475	475 Exactly. This is what I'm thinking right now (laughter).		
R78		476	476 (laughter)		
P78	Work environment/loss control (L477)	477 478 479	<p>477 I guess it just must be sometimes I <u>feel like it is getting in the way</u> and I'd like to not think about it or talk about it to anyone at work, so it's <u>not getting in the way</u>.</p> <p>478</p> <p>479</p>	Headache getting in the way (of work) (L477)	<p>Not think about headache at work (L478)</p> <p>Not talk about headache at work (L478-L489)</p> <p>By not talking or thinking about headache is associated with not getting in the way of work (L489)</p>

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R79		480	Getting in the way of?	
P79	Work environment (loss of control) L481 Critical self-dialogue (L481-L482)	481 482 483	My (pause 5 seconds). Yeah. I want to say my work; I should be saying my wellbeing. But erm yeah, yeah just getting in the way, just something that's on my mind.	Headache getting in the way of work (L481) Should be saying getting in the way of my wellbeing (L481-L482)
R80		484 485 486 487	It's interesting you've said "work but I should be saying wellbeing". It's your experience, it's, it's, why you've taken medication and that's what I'm interested in hearing not what you would want me to hear.	
P80		488	Yeah, yeah.	
R81		489	That's really important for me. So in your office Ibuprofen.	
P81		490	I guess it just must be because it hurts too much I guess...	
R82		491	Hmm.	

EXPERIENCES OF LIVING WITH AND MANAGING ETTH IN ADULTS: AN IPA STUDY

P82	Martyrdom (L492-L493)	492 493	... Or I feel, I know I'm not going to go home. <u>I know I'm never going to, from a headache, I wouldn't let myself go home.</u>	Not go home from work as a result of headache, (associate this with taking medication) (L492-L493)
R83		494	Right. Okay, that's interesting.	
P83		495	So yeah I guess that's...	
R84		496	What makes you stop going home? If pain is so adverse.	
P84	Normalisation (L497)	497	Well I guess it isn't that. <u>It can't be that adverse.</u>	Pain from headache cannot be adverse (L497)
R85		498	Tell me more.	
P85	Minimisation (L499-L501) Critical self-dialogue (L502-L503)	499 500 501 502 503	It can't be that bad. Erm, like if I felt dizzy or vomiting or nauseous then I'd go, but from a headache, from that kind of background noise that's not going to happen (laughter). Erm but I guess sometimes it is adverse and I don't feel like, yeah I feel like I should do more and that's when I take the pills.	Headache described as background noise which is not bad as vomiting/sickness association with no going home (L499-L501) 'Should do' more (saying this to one self) which is then associated with medication (L502-L503)
R86		504 505 506	Ah...so you're doing more is not going, for you is not, it's not, it's not good enough going home. It's taking the medication then and that's when the Ibuprofen comes out then.	
P86		507	Yeah I guess.	
R87		508	Mmm.	
P87		509	That's as clear as it is to me, I'm not sure if that's...	

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R88	510 511 512 513 514	No no it is clear. It's clear because you've mentioned not getting in the way, self-acknowledgment and not applying it to others at work. Clearly you are someone who, works really important for you and pains not going to get in the way. It's interesting when you mention wellbeing, "I should say wellbeing."	
P88	515	(Laughter). Should.	
R89	516 517 518 519 520	But you have been mentioning wellbeing but you haven't been using the word. You've mentioned exercise, you've mentioned water, all parts of wellbeing I suppose. Yeah. Anything else you want to tell me about what's, actually let's go back, lets, how do you perceive your head pain?	
P89	521	How do I perceive it?	
R90	522	How do you perceive your head pain?	
P90	523 524	Erm...arh, can you give me a que word or something. How do I perceive it?	
R91	525 526 527 528 529	How do you see it, so if I was to say, if someone asks me how do you perceive the door I would say it's got a handle, if I was, if I was in another town? How do you perceive the door to the lab I'd say yeah... So how would you perceive, how do you perceive your head pain?	
P91	530	Erm (cough). The physicality of it to me you mean? Or...	
R92	531	Yeah the way you perceive it in terms of...	

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P92	532 533	How do I perceive it...(exhales)...erm...so it is... [inaudible words] I guess it's so kind of familiar it's hard to, erm...describe.	
R93	534	It's difficult?	
P93	535 536	It is difficult...Erm (pause 3 seconds). but I suppose the fuzziness is something that kind of... yeah.	
R94	537 538	Erm the fuzziness. Is that something you mentally depict or is that something you use in words?	
P94	539 540 541 542 543	Mmm, I just say a headache if anyone asks. I've got a headache again. Erm (pause 4 seconds), erm. I guess I don't see it; I don't visualise it. I guess the background noise is probably my thing. In terms of where it would be it's usually at the front of my head. Erm...	'Just' headache if anyone asks (L539)
R95	544 545 546	You mentioned background noise a few times. Can you tell me a bit more about background noise, the words you've used are quite interesting?	
P95	547 548	As in, I've become, I'm aware of it or in the background sometimes, sometimes ignore it so I can get on with work stuff.	Focus attention on headache - sometimes (association with background noise one mentioned) (L547-L548) Other times not focus attention on headache (background noise) and carry on with work (L548)
			Self in control (L547-L548) Compartmentalisation (L548)

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R96		549	And does that, does that come more with sort of pain when you're experiencing head pain?	
		550		
P96	Mindfulness (L552)	551	Erm, so it's not there every day but it is there fairly often. Erm, <u>the more intense it is</u> . I guess <u>the more, the more I think about it</u> .	Thinks about headache when it becomes intense (L552)
		552		
R97		553	So when you say background noise you mean about people around you, click...	
		554		
P97		555	No, just it's in the background of my head.	
R98		556	The background of your head. Oh okay.	
P98		557	Does that make sense?	
R99		558	Yeah.	
P99	Rationalisation (L562-L563)	559	I don't think I'm particularly sensitive to other people's noises, but because of the head pain I am, I do notice them. Erm, yeah, but again I would say that things that annoy me or being more sensitive to things like that is <u>because of being tired rather than pain</u> .	Because of being tired rather than pain that one gets annoyed (L562-L563)
		560		
		561		
		562		
		563		
R100		564	Mmm, mmm. So being annoyed, you've mentioned tiredness, you've mentioned other things as well, previously and you've distinguished between the two in terms of what you're in control of and what you're not. How does it make you feel when you're annoyed at yourself?	
		565		
		566		
		567		
		568		
P100		569	(pause 2 seconds) Erm...	

EXPERIENCES OF LIVING WITH AND MANAGING ETTH IN ADULTS: AN IPA STUDY

R10 1	570 571	I know it's really hard when we're actually discussing this, I know it's quite difficult.	Annoyed at oneself for background noise (previously referred to as headache) (L572) Not sure, if get angry at self when head hurts (L573-L574) One things it is not helpful when annoyed at self – said with laughter (L574-L575)
P10 1	572 573 574 575	Annoyed at myself because of the background noise in my head. Erm, I don't know if I get annoyed with my, I don't get angry with myself because of the fact my head hurts. I don't think. I don't think that would be very helpful (laughter).	
R10 2	576 577	Okay. It's just that you mentioned the word annoyed and I just wanted you to elaborate on that word annoyed.	
P10 2	578 579 580	(pause 3 seconds) I mean if we were having this interview in the afternoon I might be giving you a different set of answers about how annoyed I am. (Laughs)	
R10 3	581	Okay. Okay. Still.	
P10 3	582	Hmm... yeah it must sap away at my resources and annoy me.	
R10 4	583	Mmm, and what resources would they be?	
P10 4	584 585	Yeah how long I can keep going and saying "Yeah, it's not getting in my way". As oppose to "it is getting in my way".	Not getting in the way in a conversation when it really is getting in the way (headache) (L584-L585)

EXPERIENCES OF LIVING WITH AND MANAGING ETTH IN ADULTS: AN IPA STUDY

R10 5	586 587	Mmm. It seems to be a really big part of your experience of head pain this thing about getting in the way...	
P10 5	588	Yeah.	
R10 6	589 590	...and not allowing it to get in the way. That's what I'm, I'm only regurgitating back what you've said to me.	
P10 6	591	Yeah. I think that's fine.	
R10 7	592 593 594	Mmm, mmm. Okay anything else in terms of, erm...things, things you may have found affective in terms of managing your pain. I know you've mentioned quite a few of them actually.	
P10 7	595 596 597 598	(pause 4 seconds). No I think that, I think I've probably gone through all my standard list; food...alcohol.... I sometimes just go, "screw it" and maybe it will help, release...you know, lower my blood pressure and that will...	Standard list – food, alcohol (triggers) monitoring and then a screw it attitude – related to triggers being used (L595-L598) Triggers help to lower blood pressure (L598)
R10 8	599 600 601	Ok so when you just fall all out and say, "right ok, sod it...I'm off with the girls" and you know, you've mentioned relaxation with them. What happens afterwards?	
P10 8	602	Erm if, the next day? (Laughs).	
R10 9	603	(Laughs) Yeah the next day.	

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P10 9		604	I do get very, very bad hangover headaches. Very bad.	
R11 0		605	And so how does that...what are you feeling at the time?	
P11 0	Loss of control (L606) Self-medicate/use of medication (L606-L607) Critical self-dialogue (L607)	606 607 608	Here we go again, usually. Where are the drugs? 'because I'll definitely medicate that one and I should drink more water (laughs).	Here we go again related to day after drinking alcohol and occurrence of headache – here we go again to oneself (L606) Definitely medicate headache which has occurred as a result of drinking the day before (L606-L607) 'Should' drink more water (L607)
R11 1		609 610	And what impact does that have? Any other impact that has on your thinking, the next day then.	
P11 1	Feeling of guilt (L611)	611 612 613 614 615	Erm..erm, I'm sure there are regrets, the standard. I don't tend to say I'm never doing this again. Definitely as I've got older it happens less and less. Presumably I am learning very slowly but yeah it's not going to, I'm not going to not do it because of... yeah.	Impact of headache next day associated with regrets, mentions standard in relation to regrets (L611)
R11 2		616 617	Okay. That's interesting. So going back to work and that, sort of, having things going on in terms of, you know you've mentioned	

EXPERIENCES OF LIVING WITH AND MANAGING ETTH IN ADULTS: AN IPA STUDY

		618	during the day, erm deadlines, you've mentioned an exact	
		619	deadline, viva being an example of that actually, a prominent	
		620	example. Erm, do you think, does that have a big, erm, weekend's	
		621	you're not working. I'm assuming you're not working here at	
		622	weekends. How are you then?	
P11		623	(pause 4 seconds). It doesn't, I guess (pause 3 seconds). Yeah I	
2		624	guess I don't normally have headaches unless there's, again	
		625	alcohol (laughter). Erm, yeah. I guess the routines different as well	
		626	and doings lots, so I can attribute things to different things.	
R11		627	Sure. Yeah. Do you want to tell me, a bit more about your routine?	
3		628	You talked about attributing...	
P11	Self-regulatory (L630)	629	Yeah, I don't know what I...I guess I meant erm, usually you	Dinner/breakfast later – change to routine associated with headache (L630)
3		630	know, <u>dinner and breakfast might be later</u> erm and things can	
		631	change from weekend to weekend depending on where I am.	
	Self-blame (L633-L635)	632	Erm... mmm. I don't know I haven't really thought about	
		633	weekend head pain. (pause 2 seconds) <u>I guess rightly or wrongly</u>	Headache week day stress and weekend its one's fault (L633-L635)
		634	<u>I assume because the week days' stress headache pain and</u>	
		635	<u>weekend if there's pain then that's my fault. It is my fault.</u>	
R11		636	Arh, that's interesting.	
4		637	Erm...hmm.	
P11				
4				

EXPERIENCES OF LIVING WITH AND MANAGING ETTH IN ADULTS: AN IPA STUDY

R11 5	638 639 640 641 642	Can you tell me a bit more about the weekend headache and week day headache because you have said that the two headaches associated with weekday and weekend are associated with headache and you mentioned it's your own fault? Would you like to tell me why?	
P11 5	643 644 645 646 647	I guess in the weekday I can't, because I'm still, I think it could be anything, obviously various things, including work stress. <u>I'm not sure which part of work is stressful because I enjoy work at the same time so it's just part of...again it's kind of, just part of the package of working...so, yeah.</u>	Enjoy work but associate with stress and headache but unsure which part is stressful (L644-L646) Justifies work, stress and headache as being part of the package (L646-647)
R11 6	648 649 650 651	Yeah you definitely sound like you enjoy work and works very important to you. It's really interesting you've made the distinction between the two and you're sitting there and even you've looked sort of...	
P11 6	652	(Laughs)	
R11 7	653 654	...because you've not been able to talk about this before, definitely.	
P11 7	655	<u>No I haven't.</u>	Not been able to talk about headache before (L655)

EXPERIENCES OF LIVING WITH AND MANAGING ETTH IN ADULTS: AN IPA STUDY

R11 8	656	Yeah. Erm, okay. Anything else you wanted to tell me?	
P11 8	657	Erm (pause 3 seconds) I... about my own head pain probably not.	
	658	I'm very interested to hear about what, what kind of things you	
	659	would be looking for.	
R11 9	660	Okay. I will stop the interview and we can discuss.	

(R=RESEARCHER & P =PARTICIPANT)

Appendix J

Ethics approval

E-mail correspondence

From: Leigh Taylor [Leigh.Taylor@uwe.ac.uk]
Sent: 01 March 2016 10:19
To: Devinder Rana-Rai (Student - SOLS)
Cc: Elizabeth Jenkinson; Devinder Rana-Rai
Subject: RE: UPDATED ETHICS SUBMISSION PROFF HEALTH PSYCHOLOGY REF HAS/14/03/54

Hi Devinder

Thank you for your email in response to your conditions.
I can confirm that the Committee have now given you full ethical approval.

Kind regards

Leigh

Leigh Taylor (Mrs)
Team Leader (Committee Services)
Research Administration
Research, Business & Innovation
University of the West of England, Bristol

Leigh.Taylor@uwe.ac.uk
Tel: 0117 328 1170

<http://rbi.uwe.ac.uk/resadmin.asp>

From: Devinder Rana-Rai [mailto:Devinder2.Rana-Rai@live.uwe.ac.uk]
Sent: 15 February 2016 16:48
To: Leigh Taylor; Research Administration; julie.woodley@uwe.ac.uk
Cc: Elizabeth Jenkinson; devinder.rana-rai@bcu.ac.uk
Subject: UPDATED ETHICS SUBMISSION PROFF HEALTH PSYCHOLOGY REF HAS/14/03/54

REF: HAS/14/03/54

Dear Leigh (and ethics office).

Please find attached an update to my previous ethics submission.

Since the outcome received, I interrupted my studies.
Since returning, I have submitted an updated form which takes into consideration a new time frame for data collection, as well as a few changes which have been made (which also considers the conditions which were suggested as well as having the benefit of completing a progression report and progression VIVA).

Attachment 2: is the updated version

Attachment 3: tracks the changes I have made based on the previous submitted form.

I have cc'd my supervisor in who has approved these changes and my submission via e-mail.

Thanks
Devinder

Letter



Faculty of Health & Applied Sciences
Glenside Campus Blackberry Hill
Stapleton
Bristol BS16 1DD Tel: 0117 328 1170

UWE REC REF No: HAS/14/03/54

Date: 3rd April 2014

Devinder Rana

Dear Rana

Application title: Exploring the coping strategies of adults experiencing Episodic
Tension Type Head Pain: An interpretive phenomenological analysis

- 1) Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed with the following conditions:
 - 2)
 1. Participants are reassured that they are anonymous (section 6) but their names and contact details are known to the researcher (and necessary given the phone screening). We think the student needs to go back through the application and make sure that this is clear. She can assure confidentiality but not anonymity.
 2. The student does not give a clear or convincing rationale as to why participants are interviewed twice. Given that interviews can be up to 90 minutes each (as stated in the application), we would question whether it is reasonable to ask participants to do this. Why not simply interview 6 participants?
 3. We are not convinced as to why head pain that is menstrual related is being excluded here – again if the student wants to do this then they need to give a clear rationale. Exclusion is likely to have the effect of excluding women from

the sample. Also for some participants, they may not be sure if their headache is related to menstruation or menopause.

4. We would like the student to give some info about their training to use the screening questionnaire.
5. The student has decided to screen out participants with mental health problems. She indicates depression but not clear if the participant could take part if depression diagnosis was some years ago? Or is the student referring to active diagnoses? Given that roughly 1 in 4 people will experience depression in their lifetime, she may be unnecessarily excluding some participants. It may be appropriate to set the exclusion criteria as current diagnosis of dementia, psychosis, or other psychiatric condition which means that the participant is unable to give meaningful informed consent.

If these conditions include providing further information, please do not proceed with your research until you have full approval from the committee. You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at

<http://www1.uwe.ac.uk/hls/research/researchethicsandgovernance.aspx>.

Please note that any information sheets and consent forms should have the UWE logo.

Further guidance is available on the web:

<http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx>

The following standards conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any

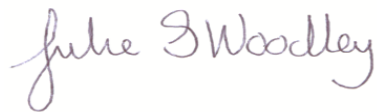
changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

We wish you well with your research.

Yours sincerely

A handwritten signature in purple ink that reads "Julie Woodley". The signature is written in a cursive, flowing style.

Dr Julie Woodley

Chair

Faculty Research Ethics Committee c.c *Liz Jenkinson*

Appendix K

Debrief

Researcher debrief notes for interview

1. To close the interview with the participant, asking them how they are feeling and if they would like to discuss anything else.
2. Hand a sheet which lists additional support and details of myself and my supervisor, should there be any questions.
3. Like I said in the information sheet which you have a copy of, this study is to explore how individuals like yourself live with and manage ETTH. This interview will now be sent to a professional transcriber who will transcribe this interview. After this, I will send the transcription back to confirm that you are happy with the accuracy of the transcription. You will also be free to let me know if you would like to remove any material or withdraw your transcript from the study – this will be done by e-mail. Additionally, just to remind you that the interview could also be listened to by my supervisors/examiners on the doctorate. All information on paper will have names removed before I begin data analysis and any information for the purposes of the doctorate/publication will have your name removed (and any other names/places of work you refer to).

Participant debrief sheet



FOR FURTHER INFORMATION

Devinder Rana-Rai (lead researcher) and Dr. Elizabeth Jenkinson (supervisor) will be glad to answer your questions about this study at any time. You may contact us at

Devinder Rana. Telephone: 07812247106 E-mail: devinder.rana-rai@bcu.ac.uk

Dr. Elizabeth Jenkinson. E-mail: Elizabeth2.Jenkinson@uwe.ac.uk

If you want to find out about the results of this study, you should contact Devinder Rana-Rai via e-mail up until one month after the last interview has taken place.

SUPPORT

You may want to contact one of the following, if you feel that you would like to talk further about issues which may have been highlighted during the interview or are looking for further support:

Your general practitioner

The Migraine Trust: <https://www.migrainetrust.org/> The migraine trust is the health and medical research charity for migraine in the United Kingdom

Migraine Action: <https://www.migraine.org.uk/> The national advisory and support charity for people affected by migraine

Migraine Support Group: <https://en-gb.facebook.com/MigraineSupport> Face book support webpage sponsored by Migavent.com

Appendix L

Information sheet



PROJECT TITLE

The lived experiences and management of episodic tension type head pain (ETTH) in adults

Invitation

Thank you for your interest in taking part in this study which will be exploring the experiences of episodic tension type headache. The following information details information about the study. Please read this carefully. If you are happy to take part in the study after reading this information sheet, please sign the consent form and return as a scanned copy on e-mail or electronic signature. The researcher will then get in touch with you. The aims of the study are as follow:

- To examine the lived experiences of adults diagnosed with episodic tension-type head pain;
- To explore how individual, manage ETTH

The research project is being led by Devinder Rana-Rai and is being supervised by Dr. Elizabeth Jenkinson for the partial fulfilment for the Professional Doctorate in Health Psychology. This research project is affiliated with the University of the West of England and the project has been approved by the University Research Ethics Committee/Faculty Research Ethics Committee – Health Sciences at the University of the West of England in Bristol.

Am I eligible to take part?

You will be eligible to take part if you MEET WITH THE FOLLOWING:

You have EPISODIC TENSION TYPE HEADACHE at least 10 episodes of headache occurring on 1-14 days per month on average for a minimum of 3 months; Your headaches last from 30 minutes to 7 days;

You have at least two of the following characteristics: a) bilateral location (head pain which is located on both sides of the head “feels like a tight band around the head”); pressing or tightening; mild or moderate in intensity; is not aggravated by routine physical activity i.e. walking or climbing the stairs; your headaches are not associated with nausea or vomiting and you have no more than one of photophobia or phonophobia; and your headache is not accounted for by another headache diagnosis.

If you meet with the above headache criteria and are aged between 18-65 years of age and can speak fluent English, then you will be eligible to take part in the study.

You will be unable to take part in the study if you have a diagnosis of dementia, psychosis or a psychiatric illness.

What will happen next?

If you are happy that you meet with the above criteria, then please date and sign the consent form attached. This can be sent as a scanned copy or with an electronic signature back to the researcher’s e-mail address. Once the researcher has received your signed copy, she will get back to you with an interview date and time.

A print copy of the consent form will be available when you attend your interview which you will be asked to sign again. One signed copy will be given to you and the second copy will be retained by the researcher.

Interview. The semi- interview will be audio-taped which will consist of yourself and the lead researcher. The researcher will ask you two open-ended questions which will frame the interview conversation about your experiences of head pain. The questions will primarily explore your experiences of living with episodic tension type head pain; how this impacts on yourself and your day to day functioning; as well as how

you may manage your head pain. You will only be required to attend one interview.

Please note: if on the day of the interview you are experiencing head pain, another interview time will be arranged.

Time commitment. The study will consist of one interview which will last between 45 minutes to 90 minutes. The interview can take place face to face in the psychology interview room at
Department of Psychology, Birmingham City University The Curzon Building (3rd floor – psychology interview rooms) City Centre Campus 4 Cardigan Street
Birmingham B4 7BD

The overall study will commence in March and end in May and interview times will be scheduled during working hours at a time which will work for you.

Participant rights. You may decide to stop being a part of the research study at any time without explanation up until one month after the second interview has taken place. There will be no penalties applied if you decide to withdraw. You have the right to ask that any data you have supplied to that point be withdrawn /destroyed without any penalty. Consent will be sought prior to the interview taking place and will be revisited at various time points as well as written consent prior to the start of each interview. These being:

Answering questions. You have the right to omit or refuse to answer or respond to any question that is asked of you *and without penalty*.

You have the right to have your questions about the procedures answered. If you have any questions because of reading this information sheet, you can ask the researcher.

Benefits and risks. There may be a possibility that during the interview sensitive issues may emerge when discussing the impact of head pain and possible associated distress. During this time, you will be asked if you would like to continue with the interview. You will also be able to take some time for yourself if needed and

will also be asked if you would like to withdraw. You can contact your G.P., or possible support groups which are listed at the end of this information sheet if you feel you need to talk to a professional about your head pain.

The interview will enable you to discuss and share your experiences which you may find helpful. In addition to this, the results of the study will be fed back to you which will inform you about experiences of migraine (if requested). The findings may be published which will be circulated to bodies such as action migraine and health professionals who will be informed about the experience of coping when living with tension type head pain.

Cost, reimbursement and compensation. Your participation in this study is voluntary. You will receive in return for your participation feedback once findings have been written up for the overall study which you may find useful.

Confidentiality/anonymity. The data we collect does not contain any personal information. The researcher will have your name and contact details which will not be disclosed (other than to the research supervisory team when reviewing work). No one will link the data you provided to the identifying information you supplied as a number allocation will be assigned (other than to the research and the research supervisory team when reviewing work). Raw data will be looked at by the lead researcher and possibly supervisor for the purposes of analysis. Any references made to your own identify or those who you may have named during the interview will only be heard by the lead researcher but names and any other information relating to identify of yourself and named individuals will be removed when publishing material for the doctorate thesis and write up for future publications and presentation of results.

Audio files, written data will be locked with a security code and will only be accessed by the lead researcher and possibly the supervisor.

Further information. Devinder Rana-Rai (lead research) and Dr. Elizabeth Jenkinson (supervisor) will be glad to answer your questions about this study at any time. You may contact us at

Devinder Rana Tel 07812247106. E-mail: devinder.rana-rai@bcu.ac.uk

Dr. Elizabeth Jenkinson E-mail: Elizabeth2.Jenkinson@uwe.ac.uk

Appendix M

Consent Form



PROJECT TITLE

The lived experiences of episodic tension type head pain (ETTH) and headache management in men and women

Project Summary

You are being asked to take part in a research study which will be examining experiences of living with tension-type head pain. The aims of the study are as follow:

- To examine the lived experiences of adults living with episodic tension type head pain;
- To explore how head pain impacts you and your day to day functioning;

The research project is being led by Devinder Rana-Rai and is being supervised by Dr. Elizabeth Jenkinson for the partial fulfilment for the Professional Doctorate in Health Psychology. This research project is affiliated with the University of the West of England and the project has been approved by the University Research Ethics Committee/Faculty Research Ethics Committee – Health Sciences at the University of the West of England.

By signing below, you are agreeing that: (1) you have read and understood the Participant Information Sheet, (2) questions about your participation in this study have been answered satisfactorily, (3) you are aware of the potential risks (if any); (4) you are taking part in this research study voluntarily (without coercion); and (5) your head pain meets with the criteria outlined in the information sheet for episodic tension type head pain.

You have the right to withdraw at any time up until one month after the last interview has taken place and no penalties will be applied if you wish to withdraw from the study.

_____ Participant's Name (Printed)*

----- Signature and date

----- Name of person obtaining consent

(researcher to sign)

----- Signature and date

Participants wishing to preserve some degree of anonymity may use their initials (from the British Psychological Society Guidelines for Minimal Standards of Ethical Approval in Psychological Research)

Please return via e-mail.



Appendix N

Member Checking

E-mail example

016 09:00 [Click to hide](#)

Private and confidential ETTH study


  24 March 2016 14:53


Inbox


Dear Devinder

Sorry for the delay in getting back to you. I'm very happy with transcript of my interview and do not wish to remove / add anything.



Best wishes




Devinder Rana-Rai 

To: 

Attachments: (2) [Download all attachments](#)

 ETTH Interview code8.docx (44 KB) [[Open as Web Page](#)];  Letter 8.docx (56 KB) [[Open as Web Page](#)]

Sent Items 15 March 2016 17:49

Dear 

Many thanks for taking part in the study. Please find attached a letter and transcript regarding your interview – should you wish to remove anything else/or add to the interview.

Names have been removed to protect anonymity and confidentiality.

Best wishes
Devinder

Member checking letter



15/03/2016

Dear xxxx,

Please find attached a transcribed copy of the interview which recently place about your experiences of episodic tension type head pain. Where possible I have removed names and personal references that were made to maintain anonymity and confidentiality.

If you would like to remove anything else, please do so by highlighting the text in red. If you would like to add anything else, please do so in a blue colour font.

Please return the amended transcript back to my e-mail address:

devinder.rana-rai@bcu.ac.uk

Could you get back to me by Thursday the 31st of March 2016 with any changes you may have. If I do not hear from you by this date, I will assume that you are happy with the written transcript.

Once again, many thanks for taking time out to be part of this study. I hope everything else is well with you.

Best wishes.

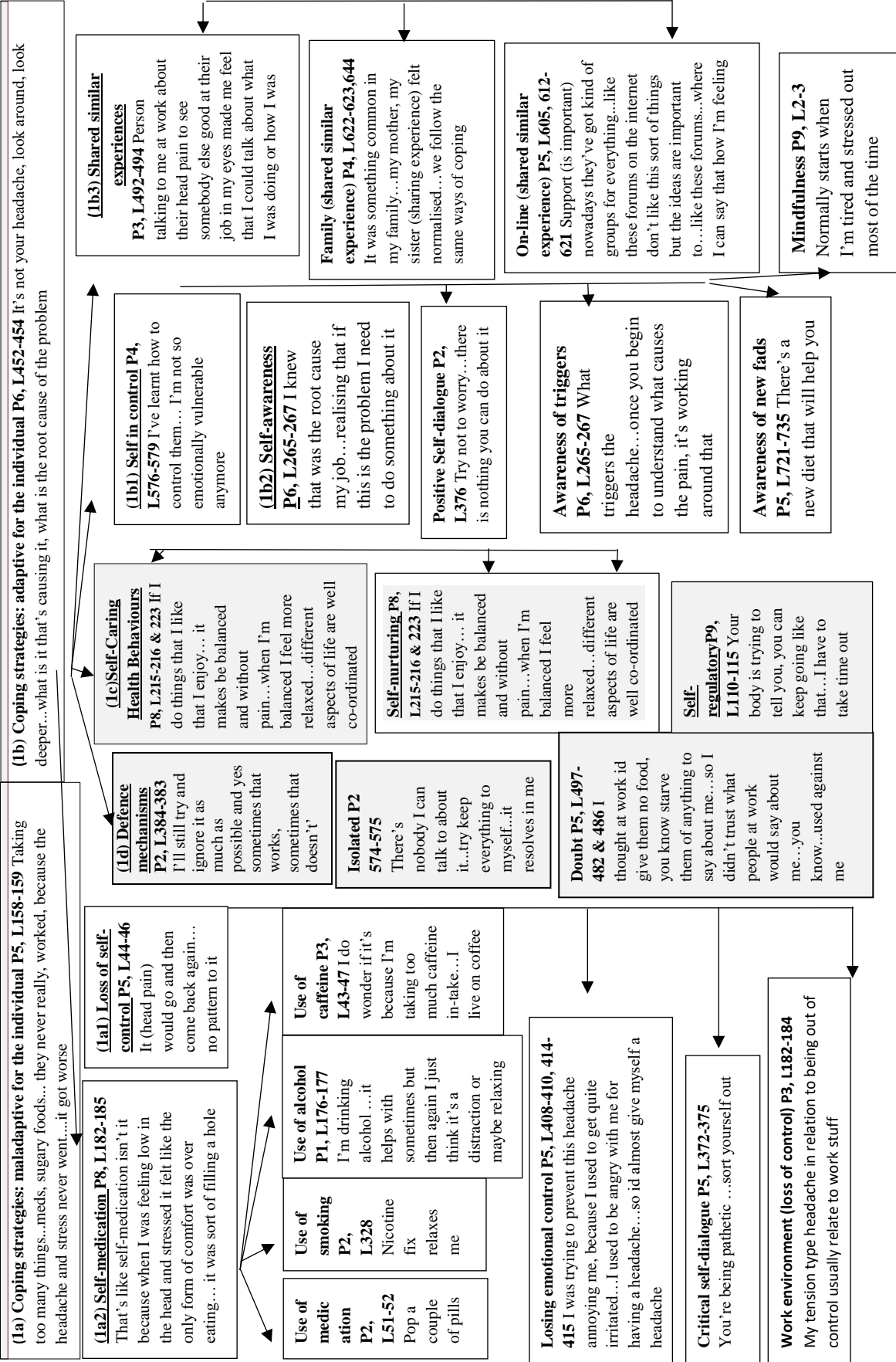
Devinder Rana-Rai

Appendix 0

Detailed breakdown of the Three Superordinate/Nine Subordinate Themes

Listed below are a further breakdown of the three superordinate themes and nine subordinate themes. Each of the superordinate themes have been presented as diagrams.

Figure 2 (1) The Essential and Versatile Use of Coping Strategies P3, L94-96 I took a step back and though I'm not getting trapped into that again...stress and headaches...I started exploring mindfulness



<p>P8, L215-216 & 223 If I do things that I like that I enjoy... it makes be balanced and without pain...when I'm balanced I feel more relaxed...different aspects of life are well co-ordinated</p>	
<p>(3c1) Physical SC P3, L727-729 If I'm drinking more than generally means I'm watching my water intake which usually means I'm thinking about what I'm eating and how I thing about healthy generally</p>	<p>Use of food (SC) P1, 415 When I have a bit more headache, I eat so I'm not hungry</p>
<p>(3b2) Emotional SC P2, L754-755, 763 Calming me down a lot at night going to sleep, is I've been putting the radio on....it breaks up that thought pattern ... stopping me over analysing things when I hear a tune that I know</p>	<p>Use of fluids (SC) P4, L303-307, 321-322 Drink a lot of water to be hydrated...even when I'm stressed I found that I feel better...when I'm hydrated...like trying to have control</p>
<p>(3b3) Behavioural SC P2, L311-313 I find it difficult to focus so I'll go for a walk again, I'll come back it will be ok for a while but there it starts so go for a walk again</p>	<p>Use of sleep (SC) P3, L62-63 Monday night I came home, had my dinner and went to bed...my brain needed that</p>
<p>(3b4) Psychological SC P6, L68-69 & 72-75 Getting over the stresses at work and stuff was challenging and I think working it out what I needed doing with my life and moving forward that eventually helped relieve the headache</p>	<p>Emotional impact (SC) P4, L576-579/ L581-583 I've learnt how to control them (head pain) I'm not so emotionally vulnerable as I have been in the past... you may be stressed or disappointed by something that happened but okay that won't last for more than hours...because you realise that doesn't really matter</p>
<p>(3b5) Spiritual SC P9, I181-182, 185 It's great (yoga)...helps me manage myself mentally and helps me manage everyday stressors</p>	<p>Emotional impact (SC) P2, L116-118 I stress myself out a lot...because I over think things, I do, I overthink everything</p>
<p>(3c) Self-regulatory P7, L710-713 I'm unlikely to say I'm stressed out I've got a headache so I'm going for a nice walk, I'm going to phone and speak to a friend...I'm going out to play football with my son</p>	<p>Behavioural impact (SC) P6, L171-174 I think I use to allow for a couple of hours and think okay well if doesn't get over by this, the next thing is to have tea and stuff, so then I'll have tea in the evening...it was almost systematic but not in a conscious way... I just got my body sort of trained</p>
<p>(3c) Self-regulatory P7, L710-713 I'm unlikely to say I'm stressed out I've got a headache so I'm going for a nice walk, I'm going to phone and speak to a friend...I'm going out to play football with my son</p>	<p>Psychological impact (SC) P8, L643-645 & 648-650 I'd look, think about my health more than getting a, a letter out within a specified period...I'm not saying I'm not doing it, but I,I, I'd do as many as I can and have my breaks and stick to my hours and if it's not done within then, the I'll have to do it then next day...</p>
<p>(3c) Self-regulatory P7, L710-713 I'm unlikely to say I'm stressed out I've got a headache so I'm going for a nice walk, I'm going to phone and speak to a friend...I'm going out to play football with my son</p>	<p>Psychological impact (SC) P3, L63-66 Related to reducing my stress levels., if you've got something to do that's making you stressed until your box off you're not gonna deal with the headache itself</p>
<p>(3c) Self-regulatory P7, L710-713 I'm unlikely to say I'm stressed out I've got a headache so I'm going for a nice walk, I'm going to phone and speak to a friend...I'm going out to play football with my son</p>	<p>Impact self-care spiritual (SC) P6, L148-149 I had constant headache pain and I felt I couldn't do anything..... then I sort of thought to myself I need to sort of work through this and train my body and mind to get through these headaches ... not allow stress to take over my life...used alternative approaches like green tea</p>
<p>(3c) Self-regulatory P7, L710-713 I'm unlikely to say I'm stressed out I've got a headache so I'm going for a nice walk, I'm going to phone and speak to a friend...I'm going out to play football with my son</p>	<p>Maintaining boundaries: P8, L215-223 If I do things that I enjoy, it makes me balanced and without pain...I feel relaxed...different aspects of my life are co-ordinated</p>
<p>(3c) Self-regulatory P7, L710-713 I'm unlikely to say I'm stressed out I've got a headache so I'm going for a nice walk, I'm going to phone and speak to a friend...I'm going out to play football with my son</p>	<p>Emotional regulation P8, L275-280 To be more sensible about things and not to take things to heart...more overview mind than being in the moment and look at the bigger picture</p>

Figure 3 (1c) The Use of Self-Caring Health Behaviours to Achieve Self-Regulation

Figure 4 (1d) The Use of Defence Mechanisms as a Way of Coping

P2, L384-383 I'll still try and ignore it as much as possible and yes sometimes that works, sometimes that doesn't

<p>Tier one</p>	<p>(1.1a1) Denial: P2, L609-610 I just pushed it to the back of my mind as much as possible</p>	<p>(1.1a2) Repression: P5, L303-304 I felt in order to be part of...I just needed to pretend that it (headache) wasn't there...because it wasn't acceptable</p>	<p>(1.1a3) Deflection: P5, L396-406 They used to always say to me...you're not your bubbly self...seem a bit quiet...seem a bit withdrawn...I'd say to them who do you think I am, somebody else?, because I'd laugh it off</p> <p>(1.1a3.1) Humour: P2, L640-643 When it's about myself (in pain), I'll always crack a joke</p>
<p>Tier two</p>	<p>(1.1b1) Minimisation: P6, L505-507 (At work) I would tell people I've got a headache but I don't think I would directly say oh it's because of work, it would just be I've got a headache today, I'm just stressed</p>	<p>(1.1b2) Projection: P7, L235-238 Some people, whenever you ask how they are they kind of real a list of symptoms...I'm reluctant to become one of those people</p>	
<p>Tier Three</p>	<p>(1.1c1) Normalisation: P4, L667-669 I feel there it is so common...it's not only you who suffers from this, there are too many people who experience different types of pains</p>	<p>(1.1c2) Rationalisation: P3, L258-259 I just grow up thinking that everybody does (have headache) ... that's it quite normal and that it's nothing and it's you</p>	<p>Key</p> <p>Tier one: 9/9 participants</p> <p>Tier two: 7/9 participants</p> <p>Tier three: 5-7 participants</p> <p>Tier four: <5 participants</p>
<p>Tier Four</p>	<p>(1.1d1) Compartmentalise: P2, L374-375 I can compartmentalise that bit and just say, just get on and do what you need to get done</p>	<p>(1.1d2) Introjection: P5, L255-256 I carried an interject...everything I heard ... there are worse things that people have to deal with...what are you moaning on about</p>	

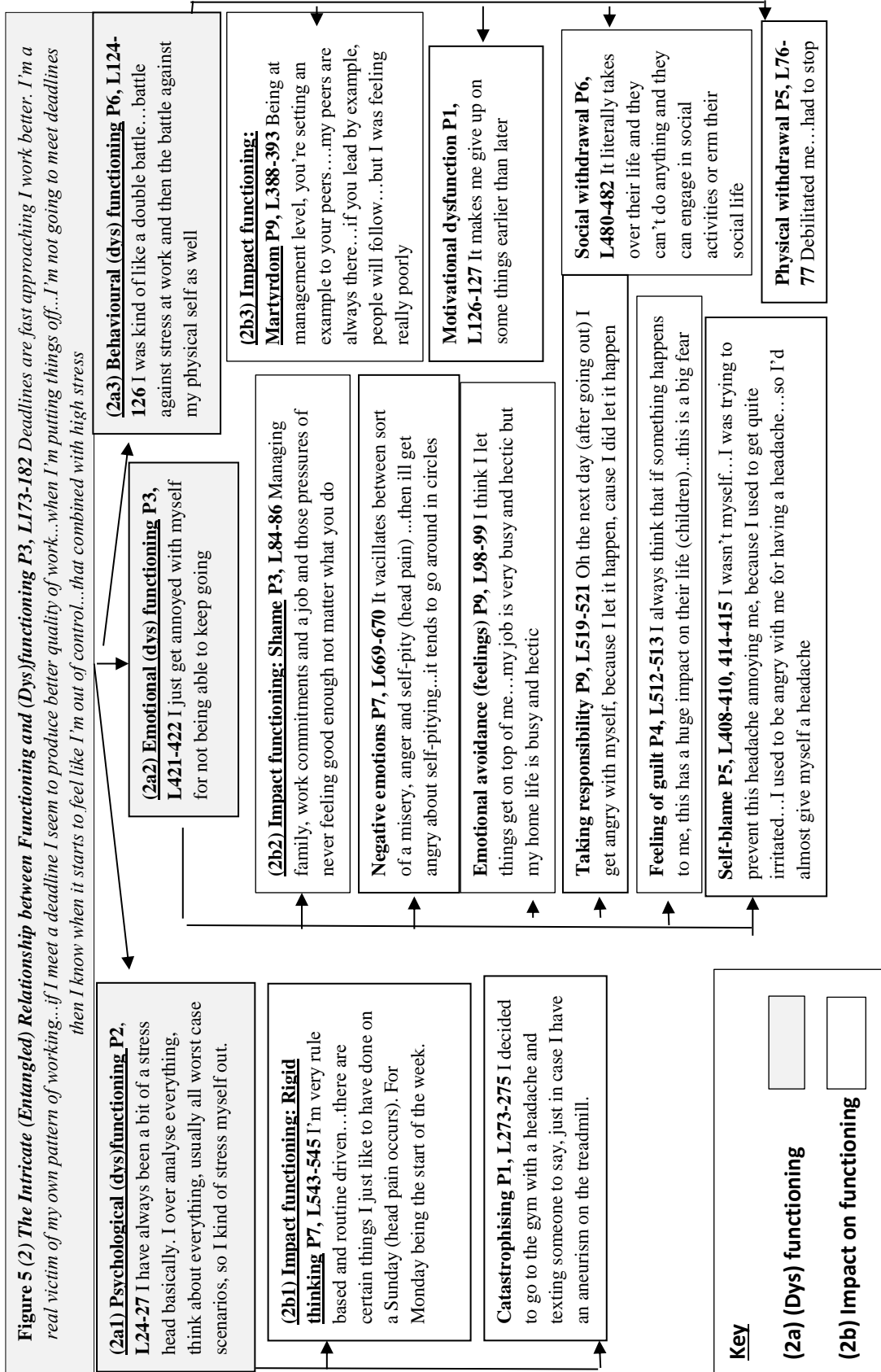


Figure 6 4. (3) A Love-Hate Relationship with Health Professionals and Medication P3, L672-674 I was worrying that my headaches had got stronger or something because (Synadol) it wasn't touching the sides... Once they took Synadol off the market... I was devastated.... I tried to sort of move away from medicine anyway ... but it's difficult and I found something else

<p>(4a) Unhealthy and unhelpful relationship with the healthcare system and medication P5, L678-691 GP made me feel insane...unheard...voiceless...lesser than...not having a position or a place, not being important...not being valued is the biggest thing...so I just carried on popping the pills by myself as usual.....back on my own with my pills</p>	<p>Inability to tell a health professional P8, L246-248 I didn't tell her (GP) that I had head pain because I never associated it with it (low mood) ...it's just, it's just an add on, that's how I feel</p>	<p>(4b) Helpful and healthy relationship with the healthcare system and medication P9, L690-693 Took time to listen to me, a relief to know that I was not terminally ill...even recommended different things like massage...taking it easy</p>
<p>Concerns about the use of medication P5, L119-121 I kind of found out (I heard) that the more tablets you...the tablets induce the headache anyway...then you've a rebound effect</p>	<p>Addiction to medication P3, L694, 696,700 Devastated (when Synadol was taken of the market) because I knew what worked for me, I just felt relief without having to go to sleep</p>	<p>Alternate professional advice P9, L87-190 There's a technique they teach you (yoga) even the deep breathing...when I went home I was using the deep breathing techniques...and I some of the stretches...which relieves</p>
<p>Concerns about side-effects of medication P7, L203-205, 207-208 I would be concerned if I was, if I was taking pain killers every other day ...i would think this isn't doing my liver any good...or if I had some other medical condition</p>	<p>Misuse of medication P2, L38-39 I don't know the reason sometimes so again I just tend to pop a couple of</p>	<p>Medication and balance P7, L172-174 When I've got a headache and it's been persistent and I know it's not going away...I take paracetamol because it helps...but only when I know it's not going to go away by itself</p>
<p>Using medication as a last resort P6, L24-26 The only time I'd take paracetamol, ibuprofen is if I couldn't...if it sorted lasted the whole night till the next day then I'd taken medication</p>	<p>Medication as a safety net P9, L227-231, 233 I always carry them (tablets)...in my handbag... in my bedroom...if at night I need to take it, it's there, even if I'm going out at night, I've got a pack...</p>	<p>Medical professional providing reassurance P2, L285-289 When she said (doctor) you're basically a stress head you need to, you need to calm down, you know, try and take yoga, try having a massage... it was such a relief... this kind of calmed me down</p>
<p>Take medication as an easy option P6, L246 I think taking medication is the easy way out to be honest</p>	<p>Intentional non-adherence to health professional advice P9, L11-12 & 16&19 Even though my doctor said I can take migraine tablets, I don't...I'll take two Anadin extras ...it kind of, doesn't get rid of it...but it suppresses it</p>	<p>Medication allowing life to be lived P9, L352-355 The tablets help me get through a busy day when I have headache and I have important things to do</p>
<p>Smugness (not taking medication) P2, L286-288 Being an example to them (family) as well, so if my husband was up all night, if he gets headache pains, I'm like look just have a cup of tea, you'll be fine...he tends to be fine...he's like you know I didn't need to take that...</p>	<p>Reliance on medication P2, L535-538 & 541 I do know that if I can't find it, I did it a couple of days ago... I was in bed with a headache and couldn't find them...and I got myself quite worked up ... and found some and that was like phew</p>	<p>Not conforming to a diagnostic label provided by a health professional P5, L594-596, 602-603 The minute I say headache (to the doctor), it's like this is it, I've become part of a group...I don't want to be in any group. I've got a headache...I don't want them to listen, I want them (doctors) to take it seriously</p>
<p>Experimenting with medication P5, L116-118 I started doing things like taking soluble things, I thought they might be better, they might absorb quicker into my system...but they weren't</p>	<p>Habitual use of taking medication P1, L423-425 When it's half past six to go home or something I'll probably take some ibuprofen or something</p>	<p>Medical professional providing reassurance P2, L285-289 When she said (doctor) you're basically a stress head you need to, you need to calm down, you know, try and take yoga, try having a massage... it was such a relief... this kind of calmed me down</p>

Appendix P
Definition of Defence Mechanisms

Table 5

Definition of ten defence mechanism

Defence mechanism type	Definition
Denial	Information of events are rejected or blocked from awareness if considered threatening, frightening or anxiety provoking (Trevithick, 2011)
Projection	People falsely attribute an intolerable, unacceptable or unwanted thought, feeling, action, or attributes onto someone else or something else (Rycroft, 1972)
Repression	A defence which wipes out from memory feelings, experiences, images, ideas or events that are experienced as shameful, painful, threatening or anxiety provoking (Brearley, 2007)
Rationalisation	Occurs when a false but reassuring or self-serving explanation is contrived to explain behaviour that arises from a repressed wish (Colman, 2009)
Introjection	A process where the functions of an external world are absorbed symbolically, or in fantasy, and replaced by an imagined object that is internalised and brought inside (Colman, 2009)
Compartmentalisation	To avoid cognitive dissonance or the mental discomfort and anxiety caused by a person's conflicting values, cognitions, emotions, beliefs etc. within themselves. (Leary & Price, 2005)
Normalisation	Automatically normalise experience to maintain a sense of self (Baigent, 2014)

Minimisation	A type of deception which is the opposite of exaggeration where the individual downplays the significance of an event or emotion (denial coupled with rationalisation) (Guerrero, Anderson & Afifi, 2007)
Deflection	A defensive act in which attention is diverted from an unpleasant thought or idea, typified in 'I'll think about it tomorrow' (Corsini, 2002)
Humour	Type of deflection where the individuals deals with emotional conflict or external stressor by emphasising the amusing or ironic aspects of the conflict or stressors, (Trevithick, 2011)

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<https://doi.org/10.1080/02650533.2011.626642>

Appendix Q

Dissemination of Results

Figure 7

Presentation at the West Midlands Psychologist in the Pub: Power point slides



“Pain is whatever the
experiencing person
says it is”

McCaffery & Beebe (1987)

Devinder Rana-Rai
West Midlands Psychologist in the Pub



Defence mechanisms

Denial *“I’ll still try and ignore it as much as possible and yes sometimes that works, sometimes that doesn’t”* P2, L384-383

Deflection & Humour *“When it’s about myself (in pain), I’ll always crack a joke”* P2, L640-643



Coping strategies

Self-medication *"Nicotine fix relaxes me"* P2, L328

Self-regulatory *"Your body is trying to tell you, you can't keep going like that...I have to take time out"* P9, L110-115

Self-awareness *"What triggers the headache...once you begin to understand what causes the pain, it's working around that"* P6, L265-267



Functioning of the self

Psychological thinking *"I'm very rule based and routine driven...there are certain things I just like to have done on a Sunday (head pain occurs). For Monday being the start of the week"* P7, L543-545

Emotional functioning *"Managing family, work commitments and a job and those pressures of never feeling good enough not matter what you do"* P3, L84-86

Behavioural functioning *"Being at management level, you're setting an example to your peers...my peers are always there...if you lead by example, people will follow...but I was feeling really poorly"* P9, L388-393



Self care

Care strategies *"If I'm drinking more than generally means I'm watching my water intake which usually means I'm thinking about what I'm eating and how I thing about healthy generally"* P3, L727-729

Self-harm *"I've probably gone through my standard list: food...alcohol...I sometimes go screw it and maybe it will help..."* P1, L595-598



Experience of the medical model

Medication as a safety net *"I always carry them (tablets)..in my handbag.. in my bedroom...if at night I need to take it, it's there, even if I'm going out at night , I've got a pack..."* P9, L227-231, 233

Not conforming to a diagnostic label provided by a health professional *"The minute I say headache (to the doctor), it's like this is it, I've become part of a group...I don't want to be in any group...i've got a headache...I don't want them to listen, I want them (doctors) to take it seriously"* P5, L594-596, 602-603

Annex One
Systematic Review

Are cognitive (and or) behavioural therapies, effective in reducing head pain and psychological distress and/or increasing coping, in adults diagnosed with migraine/tension-type head pain? A systematic review of Randomised Controlled Trials and Non-Randomised Studies

Rana-Rai (2013)

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Abstract

Objectives. To assess the efficacy of cognitive and behavioural therapies (Cbt) on reducing head pain and psychological distress (and or) increasing coping, in adults diagnosed with migraine (and or) tension-type head pain. *Methods.* A systematic review was conducted on randomised control trials and non-randomised studies; no restriction was set for date of first publication, up to 6/6/12. 10 databases were searched. *Results.* 15,917 articles were retrieved, from which, 13 Cbt trials (70% behavioural; 30% cognitive behavioural based), met with the inclusion criteria. The review comprised of 500 participants (18-65 years), diagnosed with migraine (and or) tension-type head pain. *Outcomes.* Head pain activity improved across all studies which ranged from -3% to -79%. Face-to-face biofeedback attained the largest reduction in head pain outcomes. Home-based CBT and group-home based behavioural therapy, were the most effective in the reduction of psychological distress. *Conclusion.* Cbt based interventions improve head pain outcomes, which vary according to type of Cbt intervention, mode of delivery and type of head pain outcome being assessed. Biofeedback is the most effective in the reduction of head pain, whilst home-based CBT is the most effective in the reduction of both head pain and psychological distress. *Recommendation.* To take into consideration variability of Cbt's when aiming to reduce both head pain co-morbid states of psychological distress.

Introduction

Rationale

According to the World Health Organisation [WHO], headache disorders rank into the ten most common disabling conditions (as cited in Strovner et al., 2007, p.193), which affects 91% of males and 96% of females (Lipton, Hamelsky, & Stewart, 2001; Reis, 1986; Silberstein & Lipton, 1993). The two most common headache disorders are migraine and tension-type headache (TTH) (McGrady et al., 1999). Migraine and TTH have been found to impact on both the cognitive and emotional well-being of the individual, i.e., 54% of migraine attacks coincide with, precipitating stress (Gutt & Rees, 1973; Rees, 1974; Sorbi & Tellegen, 1988); are associated with anxiety (Bromberg et al., 2011), and depression (Hammen, 2005). Furthermore, 1/3 of TTH patients, exhibit depressive symptoms (Lance, 1973).

The efficacy of pharmacological treatment for migraine and TTH is well established with the widespread prescription of anti-depressants (Oldman, Smith, McQuay, & Moore, 2002; Stillmann, 2002), but have been found to have modest effects in the reduction of head pain (Stillmann, 2002).

Cognitive and behavioural therapies (Cbt's). A number of psychological treatments have been developed for migraine and TTH patients (Rains, Penzien, McCroy, & Gray, 2005), which have consistently lead to significant reductions in head pain (Martin, 1993; Merelle, Sorbi, van Doornen, & Passchier, 2007), and a smaller number which have also been found to improve on, cognitive and emotional states (Martin, Forsyth, & Reece, 2007). More specifically, *Cbt's* have been designed to ameliorate pain, distress and disability (Fordyce, Flower, Jr. Lehmann, & DeLateur, 1968; Keefe, Rumble, Scipio, Giordano, & Perri, 2004). Recent systematic reviews have evidenced the efficacy of Cbt's, in the reduction of pain and improvement in mood outcomes, in adults with chronic pain (Morley, Eccleston, & Williams, 1999; Smeets,

Vlaeyen, Kester, & Knottnerus, 2006; Turner, Mancl, & Aaron, 2005; Williams, Eccleston, & Morley, 2012); the outcomes of which have been corroborated by meta-analysis - mean effect size of 0.36 (depression) and 0.53 (coping) (Williams et al., 2012).

Meta-analytical studies have quantified the impact of psychological treatments in the reduction of head pain, where the most recent review (9 studies: 1980 – 2001) reported a 35% to 55% improvement in head pain, compared with a 2% improvement for no-treatment controls (Rains, Penzien, & Lipchik, 2005). Despite such favourable outcomes, a systematic examination of the impact psychological treatments have on, both head pain and psychological distress, are non-existent.

Current guidelines suggest, that self-management is favoured when managing chronic diseases (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Chodosh, Morton, Guitera, & Pascual, 2005; Lorig & Holman, 2003; Lorig, Mazonson, & Holman, 1993; Lorig, et al., 1999) which address, “risk progression factors” (i.e., stress and depression); consequently are also key targets for non-pharmacological interventions (Bigal & Lipton, 2006; Buse & Andraisk, 2009).

With this in mind, the present review will, a) aim to inform practitioners about the efficacy of Cbt’s on both head pain and psychological distress, in adults diagnosed with migraine (and or) TTH, and b) add to systematic reviews which have examined the efficacy of psychological treatments on pain and psychological distress, in adults with generic chronic pain (i.e., Morley, Eccleston, & Williams, 1999; Smeets, Vlaeyen, Kester, & Knottnerus, 2006).

Stress. “*Migraine, is a periodic, stress-related, vascular reaction associated with severe HP*” (Stout, 1985, pp.531), the association of which, has been established by several researchers (i.e., Graham & Wolf, 1938; Kroner-Herwig, Diergarten, Diegarten, & Seeger-Siewert, 1993). According to Marcussen and Wolf (1949),

migraine is a consequence of a vascular stress response (Appenzeller, Davison, & Marshall, 1965; Henryk-Gutt & Rees, 1973). Simultaneously, emotional thoughts have been found to impact on the central nervous system (Knapp, 1982), which have found to also impact on the experience of head pain (Kroner- Herwig et al., 1993).

Consequently, prospective studies have found a positive relationship between head pain and stress (e.g. Kohler & Haimeril, 1990; Sorbi & Tellegen, 1988), as manipulation studies have reported elicited head pain in 69% (Gannon, Haynes, Cuevas, & Chavez, 1987) and 83% (Haynes, Gannon, Bank, Shelton, & Goodwin, 1990) of participants, which have been exposed to stress.

Anxiety. Anxiety is an aversive state of worry, fear, uneasiness, or apprehension resulting from feelings of being unable to predict, control or obtain desired outcomes (Barlow, 2000; Barlow, 2002); which has found to be a common trigger of migraine (Martin & McLeod, 2009; Martin, Milech, & Nathan, 1993). This not only has been shown to contribute to an increase in head pain (Penzien, Holroyd, Holm, & Hurse, 1985; Phillips, 1989), but also an increase in depressive symptomology (Tull, Gratz, & Lacroce, 2006).

Migraine and TTH individuals attain higher anxiety scores, compared to head pain free controls (Andrasik & Holroyd, 1980; Hatch et al., 1991), simultaneously; the occurrence of migraine is highly correlated with anxiety (Radat & Swendsen, 2004; Scheftell & Atlas, 2002). Cbt's which target anxiety have been reported to find a decrease in both, anxiety and head pain at post-intervention (Smith, Nicholson, & Banks, 2010).

Depression. Up to 50% of patients with headache disorders are found to exhibit symptoms of depression (Kashiwagi, McClure, & Wetzel, 1972) of which, 1/3 of TTH sufferers exhibit depressive symptoms (Lance, 1973); and migranuers have a 17.6% (16.6-18.6 95% CI) odds chance ratio of being diagnosed with major depression.Despite

this, only a handful of studies have primarily focused on the impact of Cbt's on co-morbid depression in migraine/TTH patients, of which, the results have been found to be in favour of treated participants.

Moderators. Whilst the efficacy of psychological treatments for migraine in adults has been considerably established (Buse & Andrasik, 2009; Campbell, Penzien, & Wall, 2010; Holroyd & Penzien, 1990; Nestoriuc & Martin, 2007; Penzien, Rains, & Andrasik, 2002; Silberstein, 2000), less is known about changes which result from psychological treatments, in adults with migraine (Seng & Holroyd, 2010).

Social cognitive and learning theories (Bandura, 1977; Bandura, 1997; Rotter, 1966) and the broader literature on self-management of chronic disease (Bodenheimer, Lorig, Holman, & Grumbach, 2002), have posited, that changing disease-specific self-efficacy and locus of control expectancies, is a central goal of self-management interventions for chronic diseases (Holroyd & Martin, 2000; Rains, Penzien & Lipchik, 2006; Tobin et al., 1986).

Coping. The association between head pain and psychological distress, has been shown to be modified by the way an individual copes with stress (Cohen & Lazarus, 1979; Lazarus, 1981; Sorbi & Tellegen, 1988), which has been evidenced in only a handful of studies (i.e. Kroner-Herwig, Fritsche, & Bruer, 1983). Sorbi and Tellegen (1988) administered, stress-coping training to 29 migranuers' and concluded, that three coping strategies significantly changed (pre to post intervention); increase in tackling problems actively, and a decrease in both avoidance and depressive reaction. This correlated with a decrease in migraine frequency, at both post-intervention, and at 12 month follow-up (i.e., Sorbi, Tellegen, & Du Long, 1989).

Headache self-efficacy (H-SE)/health locus of control [H-LOC]. H-SE is donated to, the confidence in one's ability to use behavioural skills, to prevent, and manage, recurrent HP (Bandura, 1997; French et al., 2000). The relationship between

H-SE and chronic head pain is mediated by, active and enduring efforts to prevent and manage pain and alleviate distress (Bandura, 1997). Increased H-SE has been rated by sufferers to be associated with - reduced anxiety, stress, head pain frequency and level of disability (French et al., 2000; Nash, Park, Walker, Gordon, & Nicholson, 2000). Despite this, only a few studies have measured H-SE in migranuers', who experience psychological distress (i.e., Bond, Durrant, Digre, Baggaley & Rubingh, 2004).

Objectives

To assess the efficacy of Cbt's (type of intervention/mode of delivery) on reducing HP (activity/frequency/intensity/duration) (primary outcome) and psychological distress (depression/anxiety/stress), and/or, increasing coping (incl. H-LOC/H-SE) (secondary outcomes), in adults diagnosed with migraine/TTH/combined (migraine/TTH), by conducting a systematic review of randomised controlled trials and non-randomised studies.

Methods

The strategy used to conduct the systematic review was adapted from, The Cochrane Handbook for Systematic Reviews and Interventions (Higgins & Green, 2011) and PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009).

Question

The overarching question which guided the synthesis of material was: *Are cognitive/behavioural therapies (Cbt's) effective in reducing head pain and psychological distress (depression/stress/anxiety), (and or), increasing control (coping / control / self-efficacy), in adults diagnosed with migraine / (TTH) / combined (migraine & TTH)?*

Sub-questions [Appendix U]

P.I.C.O.T

The P.I.C.O.T model (Booth & Fry-Smith, 2004), guided the research questions and the inclusion criteria for the review. Appendix A - inclusion/exclusion criteria.

Population. Age. The population of interest was adults, aged between 18 to 65 years, diagnosed with at least one of the following - migraine/TTH/combined.

Gender. Both genders were included. Studies which focused on menstrual related migraine (IHS, 2004) were excluded, as treatment targets oestrogen levels (Dowson, Massiou, & Aurora, 2005).

Psychiatric (excluded). Migraine in individuals with a diagnosis of mental disorders, tend to have head pain which is associated with psychopathological causes and related medication (Baskin & Smitherman, 2009; Ratcliffe, Enns, Jacobi, Belik, & Sareen, 2009).

Intervention - included. Behavioural. Behavioural based therapies have been found to be effective in managing head pain (Blanchard, Andrasik, Ahles, Teders, & O’Keefe, 1980; Grazzi & Bussone, 1993).

Cognitive. Cognitive based therapies which comprise of, cognitive coping skills training (i.e., Anderson, Lawrence, & Olson, 1981; Holroyd & Andrasik, 1978; Kremisdorf, Kochanowicz, & Costrell, 1981) and stress-coping based interventions.

CBT. This encompasses stress management (Sandor & Afra, 2005). CBT based interventions have been found to significantly reduce migraine related head pain (Campbell, Penzien, & Wall, 2010; Mohammadi, Sajadinejad, & Taghavi, 2008).

Mode of delivery. All modes of delivery of Cbt’s were included - face-to-face clinic based; group-based clinical/home; web-based and home-based.

Intervention -excluded. Physical therapies. [Appendix S].

Summary of literature inclusion criteria

The inclusion criteria set for this review was, a) studies which included adults (18 – 65) years, which were screened for at least one of the following -

migraine/TTH/combined; b) the intervention administered was based on cognitive/behavioural/C&b theory; c). head pain calculated according, to a minimum of one of the following head pain indices (index/frequency/intensity/duration), and measure psychological distress (depression/anxiety/stress), and or, coping (coping/control/self-efficacy); d) assessment outcomes measured at Pre/I and Po/I, and or, follow-up assessment; e) studies which were published in the English language. There was no date restriction set.

Search protocol

Electronic searches were conducted on the following databases - PsycINFO, PsycARTICLES, CINAL Plus, Medline, The Allied and Complimentary medicine (AMED) – combined search; PubMed, Web of knowledge, Cochrane and Science Direct, on the 6/6/12. Appendix B- database search, and Appendix C - MeSH terms.

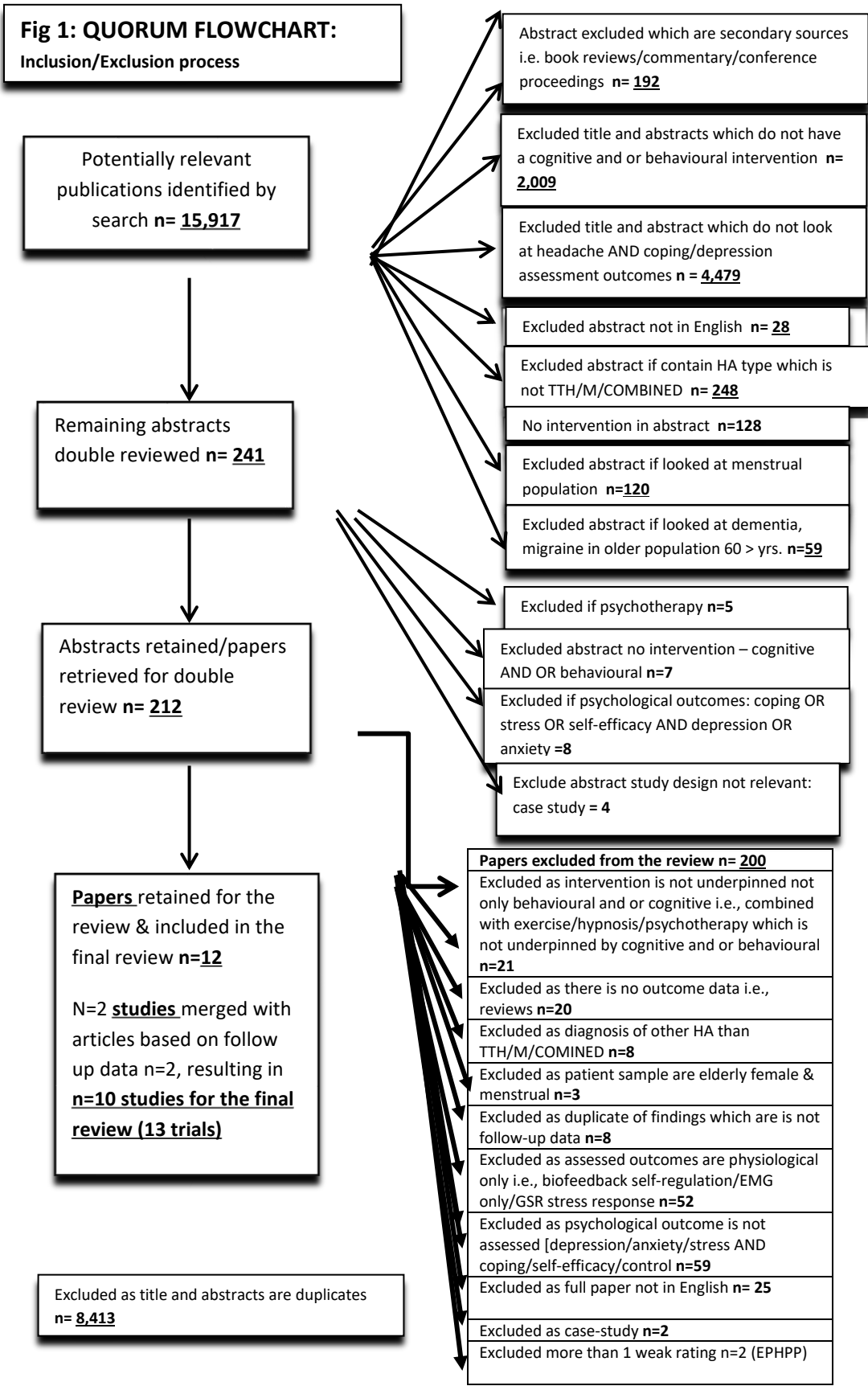
The database search retrieved n=15,917 titles/abstracts (figure one), from which, the following abstracts were excluded - n=841 duplicates; n= 192 secondary sources, and n=7071 abstracts did not meet the inclusion criteria. Consequently, a total of n=241 abstracts were reviewed, of which, a further n=24 were removed, which did not meet with the inclusion criteria.

N= 212 full papers were retrieved and were subjected to blind peer review, from which, n=200 full papers were excluded as not meeting with the set inclusion criteria Appendix D – excluded papers, Appendix E – blind review exclusion. This resulted in n=14 papers, of which, n=2 studies were merged with n=2 follow-up studies, resulting in n=12 studies (based on n=14 articles) which proceeded to quality assessment (figure 1 QUORUM flow chart).

The n=12 studies were subject to blind peer review, for data extraction and quality assessment (Effective Public Health Practice Project [EPHPP], 2004), from which n=2 studies were excluded (weak ratings) [appendix G].

Figure 2: Studies included in review

No	Authors
1	Andersson, Lunderstrom, & Strom (2003)
2	Andrasik & Holroyd (1980)
3	Bond, Durrant, Digre, Baggaley, & Rubingh (2004)
4	Devineni & Blanchard (2005)
5	Holroyd, Nash & Pingel (1991)
6	Mérelle et al. (2007); Mérelle et al. (2008)
7	Nicholson, Nash & Andrasik (2005)
8	Rokicki et al. (1997)
9	Sorbi & Tellegen (1988); Sorbi et al. (1989)
10	Thorn et al. (2007)



Results

30% of studies (n=3; 2, 3, 8) clinical control trials; 20% of studies (n=2; 5, 9) were cohort based (two group repeated measures design), and 10% (n=1; 7) was cohort based (single group repeated measures design).

Participant characteristics. The included studies treated n=500 participants which consisted of a mean age range of, 35.19 years. 70% of studies (n=7; 1,3,5,6,7,8,9) provided a mean age range (18.8 – 53.5 years). The mean percentage female to male ratio, was 85%:15%. **Diagnosis.** The included studies in the review consisted of participants which were screened for at least one of the following – migraine/TTH/combined. 60% of the studies (n=6; 1, 3, 4, 6, 7, 8) based the diagnosis according to the (International Classification of Headache Disorders [ICHD-I], 1988) and 30% of the remaining studies (n=3; 2, 5, 9) studies used various other diagnostic tools. **Head pain. Head pain type.** All participants were diagnosed with at least one of the following – migraine/TTH/combined [appendix H and I]. **Patient recruitment.** 50% of studies (n=5; 4,6,7,9,10) recruited from both practitioner and self-referral methods, 30% (n=3; 3,5,8) practitioner referral and 20% (n=2; 1,2) self-referral.

Interventions

Theoretical underpinning. The 10 studies in the review evaluated interventions that were underpinned by one of the following, or combined elements of - cognitive/behavioural/C&b theory. The larger majority of studies 70% (n=7; 2,3,4,6, 7, 8, 9) were behavioural based.

Mode of delivery. 60% of studies (n=6; 1, 4, 5, 6, 7, 9) had minimal therapy contact time [MTCT], and one study in the review (3) had no therapist contact time, which was based on a self-efficacy (behavioural) video intervention. From the 6 studies which had MTCT, (1, 4) were web-based, and (6, 7, 9) were behavioural home-based, of which, 6 was behavioural group home-based (lay trainer contact), whilst (5) delivered

cognitive and behavioural therapy, as a home-based intervention. The remaining 30% of studies (n=3; 2,8,10), involved clinic face-to-face therapist contact throughout the intervention [FTF], of which, (2, 8) delivered biofeedback (FTF), and (10) administered cognitive and elements of cognitive behavioural therapy intervention in clinic (FTF), (Figure 3 Intervention characteristics).

Comparison

Control group (CG). 60% of studies included a CG (n=6; 1,2,3,4,6,8).

Outcomes

Primary outcome. Primary outcome for the review examined head pain which was assessed, either by HP index/frequency/duration/intensity, at Pre/I and Po/I or follow-up. **Secondary outcomes.** Psychological distress was examined, which assessed at least one of the following - depression/stress/anxiety, and or, coping which examined one, or more, of the following – coping/control H-LOC/self-efficacy H-SE.

Risk of bias: included studies

Quality assessment was based on The Effective Public Health Practice Project tool for quantitative studies (EPHPP, 2004). Two reviewers independently scored all relevant articles for quality. Differences in scoring were resolved by discussion – Appendix J Quality scoring summary table. **Global rating.** 40% of studies were rated as strong (n=4; 2,6,8,10); and 60% (n= 6; 1,3,4,5,7,9) were assigned a moderate score.

Selection bias. 30% of studies (n=3; 1,6,7) were rated as strong. 70% of studies (n=7; 2,3,4,5,8,9,10) were rated as moderate, of which, 40% of studies (n=4; 6,7, 9, 10), utilised 2 or \geq methods of recruitment (clinician & self-referral -volunteer) which consequently reduced the probability of selection bias. 60% of studies (n=6; 1,2,3,4,5,8) utilised one recruitment method. Studies (1,2,4,8) recruited participants from volunteer samples (self-referral); of which, studies (2, 8) recruited from a student population; (1) from regional newspapers, and (4) from internet sites.

Studies (3, 5) recruited participants from clinical referral - Appendix E patient characteristics and recruitment methods table. **Percentage which agreed to participate.** 30% of studies (n=3; 4, 6, 7) provided information about the number of individuals which agreed to participate, all of which reached a 80% or \geq agreement (range: (7) 80% - (4) 92%). 70% of studies (n=7; 1,2,3,5,8,9,10) did not identify the number of individuals which agreed to participate. **Study design.** 70% of studies attained a strong rating, of which, 40% (n=4; 1,4,6,10) were randomised control trials (RCT); and 30% (n=3; 2,3,8) were based on a clinical control trial (CCT) design. (Appendix Q – study design and treatment allocation).

RCT and randomisation. Study (1) employed a statistician that randomly allocated participants. (1) but did not describe the randomisation method used. (10) identified random allocation by a toss of a coin, and (4) stated random allocation was used, but did not detail the type of method. **CCT.** Studies (2,3,8) were based on a CCT design, of which, (3) used random numbers and (2) employed a statistician, who randomly allocated participants via a restricted randomisation method.

Cohort Before and after 2 groups. Studies (5, 9) had Pre/I to Po/I repeated measures, for two group intervention groups which were assigned a moderate score.

Before and after 1 group. One study (7), was based on a single group Pre/I to Post/I repeated measures design, which was also assigned a moderate score.

Confounders. All studies had a two-week “run in period”, which assessed head pain activity. 80% of studies (n=8; 2,3,4,5,6,8,9,10) were rated as strong, as there were no significant difference in demographic/clinical variables of participants at base-line i.e., “*There were no differences in the dependent variables at entry into the study based on headache diagnosis.*” (10, pp.943). (6, 8) conducted within sample matching, at baseline, for head pain characteristics. (7) was not scored, as the study was a single outcome design.

Figure 3 Study Characteristics

Study	Theory	Duration	Type	Theory/therapy themes
1	(CBT based) web-based self-help (MTCT) non-therapeutic treatment modules MTCT (phone & e-mail contact only)	6 wk. period	Cognitive and Behavioural	Applied <u>relaxation</u> (behavioural) Problem-solving (cognitive)
2	Biofeedback administered by therapist - face to face - therapist and participants (pairs)	Bi-weekly x7 (1hr) sessions	Behavioural	Biofeedback - control frontal muscle tension via feedback (<u>relaxation</u> & control) (behavioural)
3	Self-efficacy self-help (MTCT) – video based	4 clips X 12 min video (1 session)	Behavioural	Based on health behaviour change model (Glanz, Lewis, Rimer, 1997) enactive experience/performance /rehearse target behaviours (role play); vicarious experience/modelling –/praise reinforcement
4	Web-based progressive muscular relaxation & coping/autogenic training/modified biofeedback (MTCT)	4 wk. x per session	Behavioural	Behavioural – <u>relaxation</u> ; monitoring; behaviour change – <u>biofeedback</u> , based on MTC manuals (Blanchard et al, 1988)
5	Home-based relaxation (combined)/ CBT (MTCT)	9 X1 hour sessions	Behavioural Some elements cognitive	Enhance <u>relaxation</u> therapy with adding CBT (stress management) (Balnchard et al 1990). Cognitive re-structuring/problem-solving strategies: avoidance vs. approach.
6	Home-based group <u>behavioural</u> training	2-h face to face group 2-4	Behavioural Some elements of cognitive	BT strategies central to attack prevention; based on established clinical protocol for individual treatment (Sorbi et al, 2000; Sorbi

	(BT-GHB) (MTCT) LAY TRAINERS			et al, 2004) modified for group intervention. Identification of triggers; use of physiological self-regulation skills; main <u>relaxation training autogenic training</u> ; breathing exercise and cue controlled relaxation learning. <u>Cognitive-behavioural self-regulation</u> i.e., breaks etc.
7	Self-administered behavioural intervention using tailored messages (SEABIT); home-based Home-based (material posted out); e-mail & phone no. (non-therapeutic) MTCT	8 weekly sessions	Behavioural	Educational component - material from Conquering Headache (Rapoport, Sheftell, Tepper, 2001); Skills training component PMR, coping; adapted from home-based treatment materials which were previously developed in a self-administered format (Holroyd, et al 2001; Holroyd, et al 1991; Holroyd, Cordingley et al, 1995; Nash et al 2004); <u>tailored messages</u> enhance SE
8	Combined relaxation/ EMG <u>biofeedback</u> face-to-face	45 min session (20 mins. testing) x 6	Behavioural	PMRT ; Blanchard and Andrasik, 1985); auditory feedback on different muscle groups 10 mins.; Biolab system; behavioural strategies monitor everyday tension and apply <u>relaxation</u> skills.
9	<u>Relaxation training (RT)/stress coping training (SCT)</u> MAIL/POSTED MTCT	9 wk. x1 hr. Plus home practice x2 daily	Behavioural And elements of cognitive	RT : <u>relaxation</u> based on <u>AT</u> manual focusing on cue-controlled breathing & muscle relaxation. SCT behavioural analysis; <u>cognitive re-structuring</u> behavioural stress coping strategies; active versus avoidance coping. Event specific coping (ECL) hierarchal stress list.

10	<u>CBT (CBT/RCC</u> treatment order) Face-to-face	10 sessions x 1.5 hrs.	Cognitive And element of behavioural	Restructuring-cognitive coping (RCC); Coping-Cognitive Restructuring (CCR) The cognitive components of the treatment manual are published in Thorn (2004) 0 1
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Blinding. All studies were assigned a moderate score, as no study in the review employed double blinding. Single-blinding varied across studies, which was used by 50% of studies (n=5; 2,6,8,9,10). The remainder 50% of studies (n=5 1,3,4,5,7), did not discuss blinding.

Data collection methods. 90% of studies (n=9; 1,2,3,4,5,6,7,8,10) were assigned a strong rating, and (9) attained a weak rating.

HP measurement. All studies calculated a head pain index (HI). HP improvement was demonstrated across all studies which ranged from - 8% (10) to 71% (4).

Drop-out (DO)

Strong Po/I. 70% of studies (n=7; 2,5,6,7,8,9,10) were assigned a strong rating as the DO rate did not exceed 19 or \geq %; which ranged from 2% (8) to 16% (6).

Appendix P- attrition table. **Moderate Po/I.** 30% of studies (n=3; 1, 3,4) attained a DO rate which fell between 20% - 39% range (moderate score); which ranged from, 23% (1) - 38% (4). **Weak Po/I.** 39%>: There were no studies in the review which met with the 39% or \geq , demonstrating good quality in relation to data attained in relation to DO's.

Follow-up assessment (FUA). 50% of studies (n=5; 3,4,6,9,10) had a FUA which also considered DO's which ranged from; (3) 1 month-FUA – 25% - (9) 36 month-FUA – 14%. Appendix P – follow up table. **Intention to treat.** 45% of studies (n=5: studies 1,4,5,6,10) conducted analyses of data where the total sample which entered at baseline, was considered at the end-point analysis.

Results of individual studies

Figure 5, depicts the results of each individual study for HP outcome – Appendix K mean percentage outcomes HP Pre/I to Po/I.

Synthesis of results

Primary outcome HP. HP at Pre/I to Post/I were measured either by, HP index (HI)/HP activity(HP-Activity) (n=5; 1,2,4,5,8); HP days-(HP-Day)/HP frequency (HP-Frequency) (n=7; 1,2,3,6,7,9,10); HP intensity (HP-Intensity) (n=5; 1,2,3,9,10) and HP duration (HP-Duration) (n=3; 1,2,9). **HP-Activity. *Within-group changes.*** HP-Activity improved across all studies which ranged from -3% (1) (n.s.) to -79% which increased to -81% at 1.5-MFU $p \leq 0.05$ (2). ***Between-group changes.*** 40% of studies (n=4; 2,4,5,8) compared HP-Activity scores between groups, all of which had an improvement in HP-Activity in favour of treated participants. The largest percentage between group mean improvement difference, was found by (2) - 72% (EMG-decrease: 79%; control group: 7%) $p \leq 0.05$. ***Intervention.*** Biofeedback (behavioural) achieved the greatest reduction in HP-Activity (2:-79%).

The two studies which achieved the lowest mean scores were both CBT based interventions (1;-5%; 10; -8%).

Mode of delivery. Two studies which achieved the highest mean improvement in HP-activity score (79% \geq) were web-based (1) and face-to-face (FTF) clinic based (2).

HP-Frequency. 70% (n=7; 1,2,3,6,7,8,10) assessed HP-Frequency. ***Within-group changes.*** 6/7 studies (n=6; 1,2,6,7,8,10) found an increase in HP-Frequency scores for treated participants. HP-Frequency improvement scores ranged from, -8% F [2,26]=3.624, $p < 0.05$. (10) to -86% (8). ***Between-group changes.*** Four studies compared a Cbt intervention with a control group (n=4; 2, 3, 6, 8), of which, 3 studies (n=3; 2,6,8) obtained a mean improvement HP-Frequency score.

Intervention. Four studies (n=4; 2,8,7,10) found a significant trend for a reduction in HP-Frequency, all of which were behavioural based interventions. Studies (1,3) failed to detect an improvement in HP-Frequency, of which, (1) was CBT and (3) was behavioural (self-efficacy) based. ***Mode of delivery.*** The highest mean

improvement score was attained by (8: -86%). 2 studies (n=2; 1,3) failed to detect an improvement in HP-Frequency, in favour of the Cbt intervention group, of which, (3) was NTC video based and (1) was based on MTCT web-based (e-mail/phone)

HP-Intensity. 60% of studies (n=6; 1,2,3,5,9,10) assessed HP-Intensity. **Within-group changes.** All 6 studies documented an improvement (Pre/I to Po/I) HP-Intensity scores, in favour of treated participants. HP-intensity improvement scores ranged from, - 3% for behavioural based (relaxation training group) (9); to - 70% for biofeedback EMG-decrease group (2).

Between-group changes. Two studies (n=2; 2,3) compared an intervention with a control group, of which, (2) found a significant between group improvement in HP-Intensity, in favour of the intervention group:

Intervention. The largest HP-Intensity improvement score was biofeedback (behavioural) based (2: -70%). The lowest improvement HP-Intensity score, was attained by (9: - 3%) which was behavioural (relaxation therapy). **Mode of delivery.** The highest improvement in HP-Intensity score was for FTF clinic based (2: -70%) and the lowest score was attained by home-based MTCT (9:-3%).

HP-Duration. Three studies (n=3; 1,2,9) assessed HP-Duration. **Between group changes.** (2) was the only study which compared an intervention to a control group and found a significant improvement in favour of the intervention group (Biofeedback: EMG - decrease: - 80% / control group -6%; $F_{3,05-.24}$, $P \leq 0.5$). **Within-group changes.** 3 studies found a significant improvement in HP-Duration in favour of the intervention group - (2) biofeedback EMG-change - 80% $p \leq 0.05$); (9) behavioural - 18% $F=3.05-9.24$, $P \leq 0.05$; (10) CBT- stress coping training -19% $F(2,26)=3.62$, $P \leq 0.05$). Study one found a non-significant improvement (1) CBT: self-help plus telephone -29% $F=7.6$, $P=.012$. **Intervention.** Largest improvement was attained by (2: -

80%) biofeedback (behavioural) followed by (1:- 29%) CBT based, and finally (9:- 18%) behavioural based (stress coping training). **Mode of delivery.** The study which depicted the largest improvement in HP-Duration FTF (2), followed by, web-based MTCT (1) and finally, home-based MTCT (9).

Psychological Distress. Depression. 50% of studies (n=5; 1, 4, 5, 7, 10) assessed depression, of which, 2 studies (n=2; 5,7) found a significant improvement in depression scores in favour of treated participants which received Cbt. The largest reduction was found for CBT (5:- 44%) which had a significant main treatment effect $F(1,33)=15.72, P\leq.001$, compared to those which received medication 28% $F(3,31)=7.32, p\leq.001$.

Anxiety. 60% of studies (n=6; 1, 2, 4, 5, 7, 10) assessed anxiety, of which, three studies (n=3; 5,7,10) found a significant reduction in anxiety. The largest reduction was found by (10) -31% in favour of CBT $F(1,30)=8.272, p\leq.0007, d=-.48$ (Pre/I to Post/I).

Stress. 30% of studies (n=3; 1, 7, 10) assessed stress which all established a significant reduction in stress scores. The largest significant reduction was attained by (7) - 26% $F(3,18)=4.82, P\leq.05, N2=0.49$ – Appendix M Psychological Distress outcome table.

Coping. Control (H-LOC). 50% of studies assessed control (n=5; 2,5,6,7,8), of which, 4 studies (studies 2,5,6,8) established a significant improvement in control. **Self-efficacy (H-SE).** 50% of studies assessed SE (n=5; 3, 6, 7, 8, 10), all of which found significant differences in favour of treated participants, of which, (7: 22%) $F=10.32, P<.01, N2=0.40$ attained the largest difference in self-efficacy scores. **Coping.** 20% (n=2; 1,9) assessed coping, both of which found significant improvements for several coping outcomes – Appendix N coping outcome table.

HP and clinical significant improvement. Clinical significant improvement is defined as a 50% decrease in HP, which was reported by 90% of studies (n=9; 1,2,3,4,5,6,7,8,10), of which, the largest number of participants which reached clinical

Figure 4
 Characteristics and
 quality description of
 measurements employ

	Stress	Depression	Anxiety	Control	Coping	Self-efficacy
1	<p>PSS (Cohen et al, 1983) 14-I IC, R (Cronbach α) of .82 (Eskin et al, 1996)</p> <ul style="list-style-type: none"> ● (SHT: 22%; SH: 15%) 	<p>HADS (Zigmond et al, 1983) 14 -I; 2 SS Good PP (Bjelland et al, 2002)</p> <ul style="list-style-type: none"> ●● (SH:33%;SHT: 53%) 			<p>CSQ (Rosenstiel & Keefe et al, 1983) 50 I/8 SS PP satisfactory (α = .70- to .80) ⁴ (Jensen & Linton, 1993)</p> <ul style="list-style-type: none"> ● (SHT:13%; SH 9%) 	
2	<p>SLEI - modelled on Holmes and Rahe (1967)</p> <p>High reliability and validity</p> <ul style="list-style-type: none"> ● (G1:1.3; G2:1.7; G3 1.6; RO: 0.4) 		<p>STAI (Spielberger et al, 1970)</p> <p>N/A</p> <ul style="list-style-type: none"> ● G1: 3.6; G2 3.7; G3 2.2; RO; 9.4. 	<p>EMG: frontal muscle (Lippold, 1967)</p> <p>High reliability and validity (Lippold, 1967)</p> <ul style="list-style-type: none"> ● Lower EMG activity (lowest in EMG DG) 		
3						<p>HMSE (French et al, 2000) LS: 1- NC at all; 10 VC. Acceptable IC (Chronbach a-.92 (time 1) & .95 (time 2) & temporal</p>

							consistency ($r = .84$) (focus group) ● SET 6%; compared to IOT & NTC; IMFU 2% X IOT - 8% IMFU 0.7%; NTC - 20% IMFU 0%.
4	CES-D (Radloff, 1977) High reliability & validity ● E 27% improvement WLC 3%	STAI (Spielberger et al, 1970) NS ● E 19% lower WLC 23% higher					
5	BDI (Beck et al, 1961) High R & V ● CBT: 79% improvement AHCL: 38%	STPI (Spielberger et al, 1979) NS ● CBT: 22% AHCL: 8%	HLOC (Holroyd et al, 1984) Modification of MHLOC (Walston et al, 1978) high R & V ● CBT: 80% control HA CBT AHCL: 20%				
6			HSCL (Martin et al, 1990) 33-I perceived control Good R in sample (Merelle et al, 2008); SS good -				HMSE (French et al, 2000) 33-I Higher score = larger confidence Good R in the sample (Merelle et

				<p>excellent IC with a Chronbach α 0.91 BT 19% Inc. (ILOC); 22% decrease (ELOC) ● WLC 4% increase (ILOC) ; 3% decrease (ELOC)</p>		<p>al, 2008); SS good -excellent IC with a Chronbach α 0.90 ● BT 16% Improvement ● WLC</p>
7	<p>BDI (Beck, Ward, Mendelson, Mock, Erlbaugh, 1961) High R & V ● 30% improvement</p>	<p>TAI (Spielberger, 1983) ● 9% improvement Reliable & valid PASS (McCraken & Zayfet, 1992) 40-I Strong internal consistency & validity ● 26% improvement</p>	<p>HSCL internal (Martin & Holroyd, Penzien, 1990) 33-I: HA controlled internally Strong validity (Martin, Holroyd, Penzien, 1990) ● 5% improvement</p>		<p>HMSE (French et al, 2000) 25-I Strong internal consistency and validity (French, Holroyd, Pinell, Malinoski, O'Donnell, Hill, 2000; Martin, Holroyd, Rokicki, 1993) ● 22% improvement</p>	<p>HSES (Martin et al, 1993) 51-I N/S ● 18% increase in SE 10% control group</p>
8			<p>EMG: Biolab system (V. 1.61) High R & V EMG: sig decrease frontals dec.6.2 Uv; right trapezius decrease = 5.7 Uv; left trapezius decrease = 6.5 Uv].</p>			

9	ECL (Sorbi et al, 1986) Based on SBS (Arrindell et al, 1984) & UCL (Schreurs et al, 1984; 1988) partly adapted from Westbrook (1979); Holmes & Rahe, 1967) ● Avoidance and depressive reaction & increase actively reducing problems (-.26; -.35; .37 M)				HSCL Martin et al, 1990) N/S E: ILOC increase 5%; ELOC 19% decrease C: ILOC 1% increase ELOC 9% decrease SCT no impact on coping behaviours (other than avoidance reduction by -.17 M diff baseline to post). ECL			
10					BDI-II (Beck et al, 1996) 21 - I Most widely used IC (range Cronbach's α = .92) & TRT R (1W) (r = .93) (Beck et al, 1996)	BAI (Beck et al, 1988) 21 I; Excellent IC – (Cronbach's α = .93) Adequate TRT R (r = .67) and convergent		HMSE (French et al, 2000) IC (Cronbach's α = .90) and CV (French et al, 2000) ● 16% increase in SE for treated

	11:29% improvement	and DV (Fydrich et al, 1992) ●45% improvement			group as a whole (PRE TO POST M)
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Figure 5 HP Pre/I to Po/I – mean change (incl. standard deviation if provided)

	HA/HI	HF/HD	TD	ED	PI/RI	MI	MF	MD	P/H A	HFD	SD
1	SHT SH 0.2 (1.2) 0.1 (0.2) 1.7 (1.3)	0.1 (0.3) 0.8 (1.0)	2.8(.04) 2.4 (1.3)		0.1 (0.4) 0.2 (0)	N/S			0.1 (0.5) 0.3 (0.1)		Little improvement Yes Sig Int. (F=7.16, P =.012) TD SHT sig decreased duration (P<.05) Reduction HI (CCS) (F=4.8, P=.064)
2	EMGD: EMGI: EMGNC: RO: <u>Pre- 1.5MFU</u> EMGD: EMGI: EMGNC: RO: 6	118 88 93 10	40 23 26 3	3 3 3 0.2	6 4 3 0.2	1 1 1 0					Yes x6 at Post & FUM F= Range 3.05 – 9.24 p=.05 EMGD X6 EMGI X4 EMGNC X2 CT RO
3	<u>Pre-IMFU</u> SET IOT NTC 0.3 -0.8 4.2	0.1 1.6 0.7	40 28 27 3	3 3 3 0.5	7 5 3 0.5	1 1 1 0					No Study not powered to detect HA differences Reasons in paper i.e., motivation etc.
4	<u>Pre-post</u> PMR/CT WLC 13 (4) 5 (0.8)					0.7 0.4 -0.6					Yes significant reduction pre to post F(1,84)=112.99, p<.0001

5	<u>Pre-post</u> CBT DRUG	1.21(0.31) 0.55(-0.17)																	36.7 (11.5) 23.8(0.75)	Yes Significantly larger reduction in HA with CBT than drug [Treatment group x treatment phase interaction] F(3,32)=2.93, p,<.05.
6	<u>Pre-post</u> BT WLC <u>Pre-6MFU</u>	0.65 (0.12) 0.2 (-0.04) XX																		No ES -0.29 effect size small therefore supporting non-significant trend (P=0.07)
7	<u>Pre-post</u> Ho. SA/Beh	6.2 (-2.8)																		Yes experienced sig less days with headache post-treatment (28 days) (n2=0.61) compared to baseline phase
8	<u>Pre-post</u> PMRT/EM G.Bio-f. AO	0.7(-0.4) -0.1 (-0.5)	-0.1(-1.1) -0.7(-0.6)																	Yes group x pre-post interaction was significant (F[2,39]=4.35, p<0.5); treated patients showed greater improvement in HA (F[1,40]=4.11, p<0.05) that AO group.
9*	<u>Pre-post</u> RT SCT <u>Pre-8MFU</u> RT SCT	-38% -30% -56% -47%	-3% -22% -16% -32%	-40% -31%	-18%															Yes significant improvement 30-40% decrease MF both groups at post F[2,26]=3.624 P<0.05 (sct), 8m fu and at

significant improvement was reported by (2) 80%. (10) failed to meet clinical significance. [Appendix P]

Discussion

Summary of evidence

All Cbt based interventions are effective in reducing HP, the efficacy of which, varies according to the type and delivery of Cbt intervention and the specific HP outcome being assessed. The most effective type of Cbt being, biofeedback (FTF behavioural); and the least effective being self-efficacy (NTCT, video based behavioural).

Clinical significant improvement in HP was not attained by participants receiving CBT (FTF group-based) whilst biofeedback (FTF behavioural) not only was the most effective in reducing HP but also attaining the largest number of participants which reached clinical significant improvement.

(CBT home-based MTCT) was found to be the most effective in reducing psychological distress, whilst self-efficacy (NTCT, video based behavioural) did not improve on self-efficacy, despite having a self-efficacy tailored intervention.

Are Cbt's effective in reducing HP. Does effectiveness vary according to Cbt type & mode of delivery?

HI/HP-Activity. All 10 studies in the review demonstrated a Pre/I to Post/I improvement in HP-Activity, of which, the level of improvement varied according to, the type and delivery of intervention.

From the review, the largest improvement in HP-Activity emanated from, biofeedback (FTF behavioural) (2), whilst the least improvement which reported by self-efficacy (NTCT, video based behavioural) (3).

Behavioural based interventions which combined biofeedback with PMRT (FTF: 8); modified biofeedback and PMRT (MTCT web-based: 4) and elements of

cognitive therapy (MTCT home-based: 9), each attained a mid-range HP-Activity improvement score, in comparison to the other studies in the review.

In contrast, delivering home-based CBT (MTCT 5) attained not only an increased improvement in HP-Activity scores, when compared to behavioural combined approaches (8,4,9), but also in comparison to participants which received medication (5).

HP-Frequency. The majority of behavioural based interventions documented a significant reduction in HP-Frequency (n=3; 2, 6, 8), of which, 2 studies administered a biofeedback based intervention (2, 8), and (6) was also behavioural based but group-home based (lay-trainers), all of which shared therapist contact time. Group/home-based contact delivered by lay trainers (behavioural) attained the highest improvement in HP-Frequency (6) even when compared to biofeedback which was delivered FTF.

HP-Intensity. All 6 studies which assessed HP-Intensity documented an improvement. Again, the largest improvement was attained by biofeedback (FTF behavioural) (2). The least improvement was documented by CBT (MTCT: self-help plus telephone web-based) (1) which showed equivocal results as self-efficacy delivered with no therapist contact (video based) (3).

HP-Duration. All 3 studies which assessed HP-Duration, found an improvement in HP-Duration, in favour of Cbt treated participants. Biofeedback (FTF behavioural) (2) attained the largest improvement in HP-Duration. On the other hand, Cbt which were designed with MTCT attained less improvement in HP-Duration i.e., Cbt home-based (9 MTCT) and CBT web-based (1 MTCT). Therefore, behavioural interventions designed with FTF contact time with the therapist, resulted in larger improvements.

Do CBT' based interventions enable participants to reach clinical significance?

The findings from the review suggest that Cbt's are effective in enabling participants to reach a clinical significant improvement in HP but with varying degrees. The largest number of participants which met with this criteria were attained by FTF (behavioural) biofeedback (2,8) and home-based behavioural (7) interventions.

Do Cbt's decrease psychological distress and increase coping?

All 6 studies which assessed psychological distress/coping, demonstrated an improvement, of which, studies (5: CBT) and (7: behavioural) found the largest improvement for depression and anxiety, of which the two studies delivered Cbt interventions which were home-based (MTCT), demonstrating that MTCT is effective in reducing depression and anxiety. More interestingly, study (5) demonstrated an improvement in depression and anxiety scores for CBT (therapy) which was greater than for participants who received medication. Interestingly, study (7) which delivered behavioural based intervention as (home-based MTCT) found the largest improvement in self-efficacy scores (coping) compared to behavioural based intervention (video based NTCT 3). Therefore, behavioural based interventions which specifically target self-efficacy are the least effective in improving H-SE in HP patients when delivered with NTCT.

Is there an association between improving HP scores and psychological distress?

Four studies found a positive correlation between HP scores and psychological distress, of which, 3 were behavioural based interventions (2, 8 biofeedback FTF) (9 combined elements of cognitive home-based MTCT); and study (1) was CBT web-based (MTCT/NTCT). Study (7) failed to find an association between HP and psychological distress which delivered home-based behavioural intervention (MTCT).

Therefore, generic behavioural based interventions which are delivered as home-based interventions (MTCT) are the least effective in improving HP and psychological distress compared to interventions which are Cbt FTF and home-based.

How do the findings from this review fit in with HP research?

This is the first review in HP which adds to previous systematic reviews that have evidenced the efficacy of Cbt's in reducing pain and improving mood outcomes, in adults with chronic pain, which have excluded HP (i.e., Morley, Eccleston, & Williams, 1999; Smeets, Vlaeyen, Kester, & Knottnerus, 2006).

Vargas and Dodick (2009) suggested that favourable treatment should not only focus on prophylactic medication, but also on the management of modifiable risk factors such as depression. This review not only supports this recommendation, but also details that CBT (5) and generic behavioural based interventions (7) are effective in reducing depression even when delivered as home-based (MTCT) interventions.

Head pain. Previous systematic reviews have shown psychological treatments to reduce HP, of which, improvement in HP has ranged from, 35% to 55% (i.e., Rains, Penzien, & Lipchik, 2005). This has not only been corroborated by the present review where Cbt interventions do not consistently lead to significant reductions.

In line with others reviews (i.e., Blanchard, Andrasik, Ahles, Teders, & O'Keefe, 1980; Rains, Penzien, & Lipchik, 2005), FTF biofeedback (behavioural) is the most effective type of Cbt, for all HP assessed outcomes.

Cuijipers, van Straten, and Anderson (2008) suggested that web-based Cbt's are effective in the reduction of HP. This review found that, when compared with non-web based Cbt interventions, web-based CBT (1 NTCT/MTCT), was only effective in the reduction of HP-Duration. More improvement was shown by, CBT based interventions which were home-based (5) and was the second most effective intervention in the review.

Psychological distress. The review supports the limited number of studies which have looked at Cbt based interventions and their impact on both HP and psychological distress (i.e., Fordyce, Flower, Jr Lehmann, & DeLateur, 1968) which have shown Cbt's to be effective in reducing pain and improving mood outcomes in adults with chronic pain (excluding HP). This review has shown that home-based CBT (5), web-based CBT (1); web-based behavioural (4); and home-based behavioural (7) are effective in reducing stress and depression in HP patients; whilst, group-based CBT (FTF), has been found to be the most effective in reducing anxiety in HP participants (10).

Control. This review has contributed to the handful of studies which have shown an increase in coping behaviours for migraine/TTH individuals who receive cognitive therapy (i.e., Murphy, Leher, & Jurish, 1990) and cognitive with elements of behavioural therapy (Kroner-Herwig, Diergarten, Diergarten, & Seeger-Siewert, 1983;). This review has shown that CBT (5) and behavioural (7) home-based interventions, are more effective in improving H-SE, compared to combined cognitive interventions which were included in this review.

Strengths and limitations

This review strongly indicates that Cbt's are effective in the reduction of HP outcomes, which vary according to the type and delivery of Cbt based intervention. Overall, it can be seen that NTCT for specialised behavioural self-efficacy interventions are the least effective in the reduction of HP, whilst FTF biofeedback is the most effective but findings may not be robust for the following reasons.

Firstly, the 10 studies included in this review varied on the type of HP which was assessed. Consequently, the data did not meet with the requirements of a meta-analysis. Secondly, all studies which met with the inclusion criteria, were published, which possibly could have overestimated the effects of Cbt's intervention. Finally, the results for some individual studies need to be taken with caution for the following

reasons. Even though the larger majority of studies were assigned a strong DO 8-16%; only 50% of studies conducted analyses which took into consideration drop-out at end-point analysis.

All participants in the review were screened for TTH and M which was a strong point of the review, as findings are applicable to clinical populations with the diagnosis of migraine/TTH. In addition to this, all studies had a 2-week run in period, which allowed HP to be recorded where 80% of studies reported no significant demographic /variable differences. In keeping with research areas which are in the early stages, this review highlighted the various assessments used to assess psychological distress and coping, which again flawed the conclusions drawn for improvements in psychological distress and coping.

Relevance of key findings

The findings from this review will be useful for both health practitioners and adults diagnosed with migraine/TTH/combined HP. This review exemplifies that, for adults diagnosed with migraine/TTH/combined HP, who are currently prescribed medication; drug based treatment has modest effects, when compared with CBT based interventions such as – CBT, Biofeedback, PMRT combined with behavioural approaches. Therefore, more effective therapeutic options are available which precede drug treatments in efficacy of improving HP.

The type of CBT therapy is also dependant on three main factors which health practitioners should take into consideration. CBT therapies vary depending on a) the delivery and type of intervention, b) the type of HP outcome which is the most distressing for the individual, c) co-morbid states of psychological distress which the HP individual may also be experiencing.

Overall, FTF biofeedback is the most effective Cbt based intervention, in reducing HP-Activity/Intensity/Frequency/Duration for HP individuals who do not

present themselves with co-morbid states of psychological distress. CBT and group behavioural interventions (MTCT- home-based) are highly effective for both the reduction of HP and psychological distress. This will help practitioners to decide which Cbt based intervention to offer HP individuals with or without co-morbid states of psychological distress.

Practitioners should also be aware that FTF based Cbt interventions (other than biofeedback), are not necessarily more effective, than behavioural and CBT home-based interventions, which are designed around MTCT.

Recommendations

The overall key recommendation from this review is that when designing or recommending a Cbt based intervention, practitioners should take into consideration that the effectiveness of a Cbt based intervention in reducing HP, psychological distress and improving coping, varies and is dependent on, the type and delivery of the intervention, as well as co-morbid states of psychological distress of the HP individual. Accordingly, the following sub-recommendations are outlined below which support the overall recommendation:

- a) Cbt approaches should be considered rather than drugs treatments alone, when aiming to reduce HP and psychological distress;
- b) Cbt should be prioritised for HP individuals with co-morbid states of psychological distress;

Conclusion

In summary, Cbt's are effective, but vary in their effectiveness according to the type and delivery of the Cbt based intervention, as well as the HP outcome type being targeted, where FTF biofeedback is the most effective compared to web-based CBT and NTCT behavioural self-efficacy therapeutic interventions. However, when co-morbid states of depression, anxiety and stress are present in individuals with HP, home-based

CBT and behavioural interventions are more effective in the reduction of both HP and psychological distress. The evidence that the large majority of Cbt based interventions are more effective than drug treatments alone, shows that more research is needed to examine Cbt based interventions in relation to HP, psychological distress and coping outcomes.

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Appendix Section

Appendix and annex	Content
A	Inclusion/exclusion criteria PICO(T)
B	Data base search
C	MeSH terms
D	Excluded articles
E	Data extraction and quality assessment sheets for studies included in the review.
F	Reviewer correspondence and agreement
G	Participant selection, head diagnosis and recruitment table
H	Summary table of quality rating (for included studies)
I	Head pain percentage calculation table
J	Head pain acronyms
K	Psychological distress outcome table
L	Coping outcome table
M	Correlation – head pain, distress and coping outcomes table
N	Head pain clinical significant improvement table
O	Attrition and follow-up table
P	Coping assessment breakdown
Q	Study selection
R	Excluded therapies
S	Diagnosis breakdown
T	Sub-questions
Annex A	Time flow chart

Appendix A

Inclusion/exclusion criteria

PICO (T) CHART

	Problem population	Intervention	Comparison	Outcomes	Types of studies
Include	1. Adult (18 -65); 2. Male/female; 3. Migraine/Tension type head/ Combined [Migraine & Tension type head] 4. Diagnosis of [3] by IHS; other diagnostic medical classification tool; neurologist.	1. Cognitive interventions; 2. Behavioural interventions; 3. Combined – Cognitive behavioural therapy interventions.	1. Waiting list control; 2. Treatment as usual; 3. Drug; 4. None.	1. Headache [frequency and or duration and or attack migraine days]; AND 2. Stress AND OR Anxiety AND OR Depression; AND 3. Control AND OR Self-efficacy.	RCT; CCT; Pre-post (if no control group has been used/one intervention only with no comparison).
Exclude	1. Psychiatric samples (depression not included); 2. Children 0 – 17 years; 3. Elderly 65 > years ; 4. Dementia; 5. Menstrual; 6. Self-diagnosis/self-referral.	1. Hypnosis 2. Exercise 3. Intervention/therapy which is not underpinned by cognitive AND OR behavioural theoretical frameworks 4. Psychotherapy which is not underpinned by cognitive AND OR behavioural theoretical ideology		1. EMG activity alone; 2. Physiological GSR measurement of stress alone; 3. Headache measurement only; 4. Only pre OR post measurement outcomes provided of HA – OUT; CONTROL OR SELF-EFFICACY – OUT; STRESS OR DEPRESSION OR ANXIETY.	1. Case studies; 2. Observational studies; 3. Retrospective studies; 4. Studies which have not been designed with pre-post.

Appendix B

Databases searched

No	Data base name	Abstracts retrieved
1	<i>Combined database search:</i> PsycINFO PsychArticles CINAL Plus Medline AMED The Allied and Complimentary medicine	n=7,666
2	PubMed	n=2,535
3	Web of Knowledge	n= 2,054
4	Cochrane	n=24
5	Science direct	n=3,638
	Total references/abstracts retrieved	<u>n= 15,917</u>

Appendix C

MeSH terms

The following MeSH terms were used to conduct the database search: (PsychInfo Search)

Population – head type (S1) and demographics (S2)

(S1): Migraine OR “Head*” OR “Recurrent head*” OR “Tension # Head*” OR “Combined head*” NOT “Cluster head*” OR “Sinus head*” OR “Vascular head*”
AND
(S2): Adult* NOT Child* OR Paediatric OR Adolscen* OR Young OR Psychiatric OR Elderly OR Geriatric OR Menstrual OR Female
S1 + S2 = S3

(S4) “Cognitive behavio?r* therap*” OR “Cognitive therap*” OR “Computeri?ed cognitive behavio?r* therap*” OR “On – line Cognitive behavio?r* therap*” OR “Web-based cognitive behavio?r* therap*” OR “cCBT” OR “Mindfulness # cognitive therap*” OR “MBCT” OR “CBT” OR “Cognitive intervention*” OR “Cognitive rehabilitation” OR “Internet # cognitive behavio?r* therap*”
AND/OR
(S5): “Behavio?r therap*” OR “Mindfulnes*” OR “Stress management” OR “Biofeedback” OR “Acceptance # commitment therap*” OR “On-line behavio?r therap*” OR “Progressive muscl* relax*” OR RET OR “Rationale-emotive # therap*” OR “Reciprocal Inhibition therap*” OR ACT OR “Aversion therap*” OR “Dialectical behavio?r* therap*” OR “Autogenic training” OR “Behavio?r* medicine” OR “Computer* OR Web* behavio?r* therap*”
S4 + S5 = S6

Intervention – Cognitive (S4) AND or Behavioural (S5) interventions/therapies

Comparison – (S7)

(S7) NOT “Case-stud*” OR “Retrospective”
S7

Outcomes – Head pain (S8) AND Depression OR Anxiety OR Stress (S9) AND

(S8) “Head* ind*” OR “Head pain” OR “Head frequency” OR “Head intensity” NOT “Physiological outcome”
AND
(S9) “Depression” OR “Anxiety” OR “STAI” OR Stress OR “PASS” OR “HAM#”
AND/OR
(S10) “Self # efficacy” OR “Health # control” OR “Control” OR “Locus # control” OR Efficacy
S8 + S9 + S10 = S11

Self-efficacy OR Control (S10)

Final combined search strings (S12)

S3 AND S6 AND S7 AND S11 = S12

Appendix D

Full paper exclusion = 200

1	Bushman et al 2007	NE
2	Zsombok et al 2005	NE
3	Niederberger et al 2004	NE
4	Sajadinejad et al 2009	NE
5	Straube et al 2008	NE
6	Zitman et al 1992	I
7	Nestoriuc et al 2007	O
8	Nestoriuc et al 2008	O
9	Kanji et al 2006	O
10	Kang et al 2009	O
11	Bromberg et al 2011	D
12	Mizner et al 1988	M/TT
13	Souza et al 2008	I
14	Knapp et al 1982	I
15	Kroner-Herwig et al 1993	Ph
16	Soyka et al 1982	NE
17	Sorbi et al 1984	NE
18	Webach et al 1978	Ph
19	Sorbi et al 1984	NE
20	Sorbi et al 1984	O
21	Yoshiuchi et al 2009	NE
22	Pichler et al 1988	NE
23	Johansson et al 1982	O
24	Lichstein et al 1983	O
25	Schlutter et al 1980	Ph
26	Largen et al 1981	Ph
27	Lambley (1978)	CS
28	Werbach 1978	D
29	Prima et al (1979)	NE
30	Peters et al (2000)	NE
31	Peters et al (2000)	D
32	Peters et al (2000)	D
33	Pholien et al (1985)	NE
34	Pinard et al (1978)	NE
35	Selmaj (1984)	NE
36	Wallbaum et al (1990)	Ph
37	Smith (1961)	Ph
38	Juprelle et al (1990)	NE
39	Woolley-Hart (1984)	NE
40	Gunderson (1986)	ND
41	Sovak et al (1981)	O
42	Rosen (2008)	ND
43	Appelbaum et al (1990)	O
44	Cott et al (1992)	O
45	de Bruijn-Kofman et al (1997)	O

46	Blanchard et al (1980)	O
47	Blanchard et al (1987)	O
48	Engel et al (1990)	O
49	Fichtel et al (2001)	O
50	Dodick et al (2007)	ND
51	Johansson et al 1982	O
52	Kroner-Herwig et al 1988	Ph
53	Holroyd et al (1986)	O
54	Stetter et al (2002)	O
55	Hart (1984)	O
56	Radnitz et al (1988)	Ph
57	Penzien (2009)	ND
58	Nash (2003)	ND
59	McGrath (1996)	ND
60	Neuechterlein et al (1980)	Ph
61	Holroyd et al (1980)	Ph
62	Reading et al (1976)	O
63	Abramowitz et al (1984)	D
64	Diamond et al (1978)	Ph
65	Feuerstein et al (1977)	Ph
66	Carrobles et al (1981)	Ph
67	Holroyd et al (1980)	O
68	Eppley et al (1996)	I
69	Reading (1984)	Ph
70	Schlutter et al 1980	D
71	Reeves (1976)	Ph
72	Rains et al (2002)	ND
73	Reich (1989)	O
74	Reading et al (1976)	D
75	Hay et al (1971)	ND
76	Holroyd et al (1990)	O
77	Lacroix et al (1986)	Ph
78	Lisspers et al (1990)	O
79	Martin et al (1978)	Ph
80	Mitchell et al (1977)	Ph
81	Mohammadi et al (2008)	O
82	Mullally et al (2009)	O
83	Daly et al (1983)	O
84	Reich (1989)	D
85	Shukla et al (2010)	ND
86	McGrath (1999)	ND
87	Penzien (2009)	D
88	Kabela et al (1989)	PA
89	Szajnberg et al (1979)	ND
90	Richard (1978)	CS
91	Rokicki et al (2003)	Ph
92	Stout (N/D)	ND
93	Silberstein et al (2003)	O

94	Sandor et al (2005)	ND
95	Andrasik (1996)	O
96	Penzien et al (2009)	ND
97	Martin et al (2009)	ND
98	Gerhards et al (1985)	NE
99	Nestoriuc et al (2008)	O
100	Nestoriuc et al (2007)	O
101	McGrady et al (1999)	ND
102	Kroner (1982)	NE
103	Bell et al (1983)	O
104	Gauthier et al (1996)	O
105	Phillips et al (1981)	PA Patient population invalid for SR Psychiatric sample
106	Abramowitz et al (1984)	M/TT Not TT/M
107	Holroyd et al (1978)	O No psychological variable
108	Martin et al (2007)	O No depression/anxiety
109	Kroner-Herwig et al (1993)	O No psychological variable
110	Holroyd et al (1984)	M/TT Muscle contraction
111	Gunreben-Stempfle et al (2009)	M/TT Other HA
112	Lisspers et al (1990)	O No psychological variable
113	D'Souza et al (2008)	O No psychological variable
114	Holroyd et al (2001)	O No psychological variable
115	Smith et al (2010)	ND Missing data
116	Seng et al (2010)	O No depression/anxiety PA Patient population invalid for SR Elderly
117	Nicholson et al (1993)	SR Elderly
118	Murphy et al (1990)	M/TT Muscle contraction HA
119	Esterbauer et al (2005)	NE
120	McLean et al (2012)	ND Overview
121	Fumal et al (2005)	NE
122	Supiot et al (2009)	NE
123	Nakagama et al (1987)	NE
124	Sorbi et al (2010)	O No psychological variable
125	Knapp et al (1982)	O No psychological variable
126	Dittrich et al (2008)	I Exercise
127	Winkler et al (1989)	O No psychological variable
128	Mesiter et al (1999)	NE
129	Basler et al (1990)	M/TT Other pain
130	Levine (1984)	O Only depression
131	Hansen et al (2007)	O Only depression
132	Scopp et al (2003)	ND Review
133	Vandyck et al (1991)	I Hypnosis
134	Goffaux et al (2003)	NE
135	Lemstra et al (2002)	I Physical therapy
136	Grazzi et al (1993)	O No psychological variable
137	Lisspers et al (1992)	Ph EMG outcomes only
138	Jacob et al (1983)	M/TT Other HA

139	ter Kulie et al (1994)	M/TT Recurrent HA
171		
183		
197		
198	Plus 3 not have pre and post assessment	Bromberg/ ..but are relevant in relation to primary and secondary
200	Plus 2 weak quality assessment	Martin/Sharma

Total excluded full papers n=200

KEY:

NE: Not in English, I: Intervention not cognitive OR behavioural, O: Assessed outcome not coping/depression/anxiety; D: Duplicate study; M/TT: Diagnosis HA other than TT/M/Combined, Ph: Physiological outcome assessed, CS: Case study, ND: No primary data (review/commentary); PA: Patient population invalid for SR

Appendix E

Data extraction and quality assessment sheets for studies included in the review.

No	Authors
1	Andersson, Lunderstrom, & Strom (2003)
2	Andrasik & Holroyd (1980)
3	Bond, Durrant, Digre, Baggaley, & Rubingh (2004)
4	Devineni & Blanchard (2005)
5	Holroyd, Nash & Pingel (1991)
6	Mérelle et al. (2007); Mérelle et al. (2008)
7	Nicholson, Nash & Andrasik (2005)
8	Rokicki et al. (1997)
9	Sorbi & Tellegen (1988); Sorbi et al. (1989)
10	Thorn et al. (2007)

Appendix F

Data Extraction Sheet

1A. DETAILS

Study ID (assigned by first reviewer): (c) ANDERSSON, D. (2003)
Reviewer (initials): DR

Citation: Gerhard Andersson, Per Lundstrom, Lars Strom (2003) Internet-Based Treatment of Headache: Does Telephone Contact Add Anything? *Headache* 43 (353-361)
Contact details (if included): Dr. Gerhard Andersson, Department of Psychology, Uppsala University, Box 12 25, SE 751 42 Uppsala, Sweden

First reviewer only – is there a need to contact authors for clarification (circle):

0 No Contact
1 Contact

1B. ELIGIBILITY
0 EXCLUDE

1 INCLUDE
(Moderate)

If circled **0 EXCLUDE** provide reason for exclusion (refer to sections below):

B1. Population					DATA EXTRACTION
B.1.1 Is the study population 18 years or above?	Y			N= reject study	40.3 y mean 18-59y range
B.1.2 Has the study population been diagnosed with migraine, tension type head (TTH) or mixed (migraine and TTH)?	Y			N= reject study	International headache Society (IHS) MIGRAINE, TENSION-TYPE from previous clinical trial (exclude cluster type).
B.1.3 Has the study excluded participants taking anti-depressant medication/therapy/diagnosis of depression	Y				Excluded – major depression/medically unclear neurological symptoms
B.1.4 Does the study include menstrual/menopause related pain?			N	Y= reject study	
B.1.5 Does the study include women who are pregnant/post-pregnancy (first year after giving birth)			N	Y= reject study	

B2. Intervention

Intervention(s) administered in the study included

B.1.6 Population demographics

Age range Total 40.3y (mean); 18-59 y (range).

Self-help plus telephone 36.2 y (mean); 18-54y (range).

Self-help only 44.9 y (mean); 25-59 y (range)

Mean age Stated above

Setting Community/clinical (new paper and web recruitment)

Sample size and characteristics

Sample size (treatment/control)

Self-help plus telephone n=24.

Self-help n=20

Clinical control sample n=8 (data not provided)

Total sample size n=44

Drop out/withdrawal Self-help plus telephone (n= 7) 29%; Self-help 35% (n=7); overall n=14/44

Dropout (32%) . Please Note: missing data for some assessments are not considered as part of drop-out as at the same time, other assessments were completed.

Gender Self-help plus telephone female n=20; male n=4

Self-help (control) female n=16; male n=4

Total sample size female 36; male n=8

Ethnicity (if specified)not stated
 History of TTT/MIGRAINE/COMBINED
 Diagnosis YES. International Headache Society criteria for migraine, tension-type headache (cluster excluded) (combined tension and migraine included).
 Time since diagnosis (if stated) YES. PEOPLE WHO HAD HEADACHE LESS THAN 6 MONTHS WERE EXCLUDED.
 B.2.11 Circle below:
 B.2.11.1 INCLUDE YES 3
 B.2.11.2 EXCLUDE IF THERE ARE NO YES's (Y).

B.2.1 Cognitive therapy or computerised cognitive therapy	Y	N	
B.2.2 Cognitive behaviour therapy OR Computerised cognitive behaviour therapy/CCBT/Internet Cognitive behaviour therapy*/CBT/cognitive therapy/Cognitive restructuring	Y		CBT techniques
B.2.3 Mindfulness/Mindfulness based cognitive therapy*/Mindfulness based cognitive behaviour therapy*/MBCT/Mindfulness based skill*	Y	N	
B.2.4 Behaviour therapy (face to face/group or computer/internet based)/BT/Behaviour modification	Y		Behavioural techniques cue-controlled breathing
B.2.5 Dialectical behaviour therapy	Y	N	
B.2.6 Aversion therapy	Y	N	
B.2.7 Acceptance and Commitment Therapy/(ACT)	Y	N	
B.2.8 Meditation	Y	N	
B.2.9 Rationale-emotive therapy?	Y	N	
B.2.10 Stress management (relaxation)	Y		Applied and full relaxation programme
B.2.11 Behaviour modification	Y	N	
B.2.12 Biofeedback	Y	N	

Duration of headache	Self-help plus telephone	Self-help (control)	Total sample size
0.5-1 Y	0	2	2
1-5	10	4	14
6-10	3	2	5
>10	11	12	23

B3. COMPARISON

B.3.1 Was a control group used?	Y	Y=1 point N= 0 point	Self-help group plus telephone Self-help group only & clinical control sample: n=8 (6 women; 3 men) 45 y (mean) 9 (sd); duration headache 17.5y (sd=12.8) standard internet based version without telephone calls.
B.3.2. Were results generated from both the control and intervention group?	Y	Y=1 point N= 0 point	

B.3.3 Total score for this section: 2_/2

B4. PRIMARY OUTCOME

B.4.1 which primary outcome(s) associated with (depression) has been measured)?

B.4.1.2 Depression	Y=1	
B.4.1.3 Anxiety	Y=1	
B.4.1.4 Stress	Y=1	
B.4.1.5 Distress	Y=1	N
<u>B.4.1.6 Total score</u>	<u>3/4</u>	

B.4.2 which primary outcome(s) associated with (control) has been measured?

B.4.2.1 Control	Y=1	N
B.4.2.2 Self-efficacy	Y=1	N
B.4.2.3 Mastery	Y=1	N
B.4.2.4 Coping	Y=1	
B.4.2.4 Other measurement of control	Y=0.5	
<u>B.4.2.5 Total score</u>	<u>1/3.5</u>	

Total score 4 /7.5

Score of 0 =EXCLUDE Score of 1>=INCLUDE

B5. SECONDARY OUTCOME

B.5.1 which secondary outcome(s) have been measured?

B.5.1.1 Head pain/head index (measured via physiological measurements)	Y=3	
B.5.1.2 Pain (measured via questionnaire)	Y=2	N
B.5.1.3 Self-report pain	Y=1	
B.5.1.4 Other measurements of pain	Y=0.5	N
B.5.1.5 Total score	<u>4</u> / <u>6.5</u>	

Total score 4/6.5

B6. DATA

Is there a baseline	Y=1
Is there data (before and after intervention for both control and intervention group)	Y=2

Total score 3/3

B.7 Pain outcome measurement and data

Measurement	Reliability/validity	Pre-intervention	Post 6 wk.	Post
Headache diary	<p>Web-based used in previous study (Strom L, Pettersson R, Andersson G. (2000) A controlled trial of self-help treatment of recurrent headache conducted via the internet <i>J Consult Clin Psychol.</i> 68 , 722-727.</p> <p>Rated maximum daily headache intensity between 0-5, 0=no pain at all and 5 – unbearable pain. X4 each day (recommended times 8am, 12, 4pm, 8pm) for duration of study. Also rates headache intensity and duration of headache for entire day.</p> <p>Headache index = means of noted intensity for each day summed, divided by the total number of registration days).</p> <p>Mean peak intensity (maximum intensity for each day divided by total number of headache days).</p>	<p>(SHT N=17) (SH N=13) Headache index (SHT) 4.2 (3.7) (SH) 3.2 (2.6) Headache days (SHT) 8.4 (4.4) (SH) 7.2 (2.8) Peak headache (SHT) 2.4(0.6) (SH) 2.4 (0.8)</p> <p>Rated intensity (SHT) 2.1 (0.7) (SH) 2.0 (0.8)</p> <p>Duration (SHT) 9.8 (6.3) (SH) 7.1 (4.1)</p>	<p>Headache index (SHT) 4.0 (4.9) (SH) 3.1 (2.4) Headache days (SHT) 8.5 (4.1) (SH) 6.4 (3.8) Peak headache (SHT) 2.3 (1.1) (SH) 2.7 (0.7)</p> <p>Rated intensity (SHT) 2.0 (1.1) (SH) 2.3 (0.8)</p> <p>Duration (SHT) 7.0 (6.7) (SH) 9.5 (5.4)</p>	<p>Diary data showed little improvement in either group on any of the diary variables. Significant interaction for duration (F1,28=7.16, P=.012) Post Hoc – SHT had significant decrease duration (P<.05) CLINICAL SIGNIFGANT IMPROVEMENT SHT 29% reached this criteria SH 23%</p>

B.8 Psychology – CONTROL/self-efficacy/concepts related to control measurement and outcome

Measurement name	Reliability/validity (questionnaire only)	Pre-intervention (base-line)	Post 6 week follow up	Follow-up Post-treatment
Coping Strategies Questionnaire Jensen, I, Linton, S.J. (1993)	2 single items questions and “increasing pain behaviours” subscale was excluded because of low reliability Apart from the 2 subscales which have been removed, psychometric properties of the subscales are satisfactory ($\alpha=.70$ to $.80$) Jensen, I, Linton SJ (1993) Coping Strategies questionnaire (CSQ): reliability of the Swedish version of the CSQ. <i>Scand J Behav Ther.</i> 22 139-145.	<p>Diverting attention (SH&T; N=15) 7.4 (3.6) (SH=9) 7.6 (4.6)</p> <p>Reinterpreting pain sensations (SHT) 3.8 (5.1) (SH)2.1(2.6)</p> <p>Coping self-statements (SHT) 17.7 (6.4) (SH) 16.3(5.2)</p> <p>Ignore pain sensations (SHT) 16.9 (5.1) (SH) 17.1 (3.3)</p>	<p>Diverting attention 8.6 (6.7) 9.6 (3.5)</p> <p>Reinterpreting pain sensations (SHT) 6.1 (6.1) (SH) 4.6(4.6)</p> <p>Coping self-statements (SHT) 14.7 (5.2) (SH) 18.7 (5.5)</p> <p>Ignore pain sensations (SHT) 13.7 (3.3) (SH) 18.2 (7.0)</p>	<p>Some improvements</p> <p>Significant main effect (F1,22=11.2, P=.011)</p> <p>Significant interaction (F1,22=5.6, P=.027)</p> <p>Significant Interaction effect (F1,22=5.3, P =.031) Bonferroni post hoc – significant reduction in SHT & between group diff in favour of this group</p>

		Praying and hoping (SHT) 9.1 (5.2) (SH) 13.9 (9.2)	Praying and hoping (SHT) 8.8 (5.5) (SH) 15.4 (10.9)		Significant main effect (F1,22=7.7, P=.011)
	Catastrophizing (SHT) 17.1 (7.5) (SH) 17.9 (8.8)	Catastrophizing 11.1 (8.5) 16.0 (8.3)			
	Increased behavioural activities (SHT) 11.3 (6.5) (SH) 12.0 (6.6)	Increased behavioural activities (SHT) 10.4 (5.10) (SH) 13.2 (7.4)			

B.9 Depression/stress/anxiety measurement and outcome

Measure name	Reliability/validity (questionnaire only)	Pre-intervention (base-line)	Post six week follow up	Follow-up Post-treatment	Baseline differences (favour intervention/none/not reported)
HADS-D Hospital and Anxiety Depression Scale (depression on sub-scale) Zgmond & Snaith (1983)	Good psychometric properties (Bjelland I, Dhal AA, Haugh TT, Neckelmann D (2002) The validity of the hospital anxiety and depression scale. An updated literature review. <i>J Psychosom Res</i> , 52: 69-77	(SHT N=15) (SH=9) (SHT) 5.7 (4.3) (SH) 6.8 (2.5)	(SHT) 4.5 (3.9) (SH) 4.9 (3.3)		Significant main effect (F1,22=4.53, P=.045) indicates depression decreased for both groups (interaction was not significant).
HADS-A Hospital and Anxiety Depression Scale-Anxiety Zgmond & Snaith (1983)	Good psychometric properties (Bjelland I, Dhal AA, Haugh TT, Neckelmann D (2002) The validity of the hospital anxiety and depression scale. An updated literature review. <i>J Psychosom Res</i> , 52: 69-77	(SHT N=15) (SH N=9) (SHT) 8.7 (4.8) (SH) 7.7 (4.5)	(SHT) 7.9 (5.1) (SH) 7.0 (4.8)		Not change leaving anxiety stable.

PSS The Perceived Stress Scale	Internal consistency (Swedish version) PSS has an internal consistency reliability (Cronbach) of .82	(SHT N=15) (SH N=9) (SHT) 31.3 (7.8) (SH) 28.3 (3.9)	25.7 (2.0) 24.7 (7.3)			Main effect of time (F1.22=7.1, P=.014) both groups experiencing reduced stress following treatment

B.10 Treatment characteristics

	Experimental/main intervention group	Clinical control group
Treatment model	Replication of a previous randomized controlled trial Strom, Petersson & Andersson (2000) Web-based self-help with e-mail support and telephone calls SHT TELEPHONE SH E-MAIL ONLY	
Content	Start – information regarding headache and role of psychological factors Treatment – Applied relaxation delivered in separate parts. Ost (1987) Full relaxation: tense-relax, relax only, cue-controlled breathing, rapid relaxation and application training (Strom, Petersson, Andersson, 2007; Martin, Nathan, Milech, van Kappel, 1989) Problem solving section, coping with problems in general & coping with headache related problems (Martin, 1993)	As stated in previous box but no weekly telephone groups Intervention which acts as a control for this study Clinical control trial – standard internet based version without telephone calls or e-mail contact

	Weekly telephone calls (n=6) 5-20 mins..... (focus on adherence)	
Contact	Web-version visual and audio sound files Contact therapies via e-mail Reminded if report card (weekly) not submitted	
Usage	Weekly report card for the exercises were used	
Treatment integrity	Improved on previous running of programme (Strom, Pettersson, Andersson, 2007) Underpinned by CBT techniques from previous studies RCT which have used web-based version	
Number of sessions	6 weekly treatment modules	
Length of sessions	Not stated Weekly telephone calls (n=6) 5-20 mins..... (focus on adherence)	
Intention to treat Y/N	Have all been treated but drop-out has not been considered in analysis	

B.11 Further analysis	Study design	Experimental between study with pre-treatment measures and post treatment (after 6 weeks) Mixed design analysis of variance to evaluate treatment effects with one between group factor (SHT OR SELFHELP) AND ONE WITHIN GROUP FACTOR (TIME) Does have clinical control sample group as well therefore CCT
	Setting from which sample derived	Community – newspaper and web
	Randomisation	Yes to two groups standard (SH) & plus telephone (SHT)
	Drop-out rate/withdrawals	(SHT) 29% (SH) 35% NOT STATISTICALLY SIGNIFICANT No diff between completers and drop outs,
	Analysis test	Mixed design analysis of variance Chi test (clinical significance)
	Post-hoc	Bonferroni corrected t tests

EPHH (Effective Public Health Practice Project): Quality assessment tool for quantitative studies

C.1 SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1. Very likely
2. Somewhat likely – webpage for the study and regional newspapers (not-likely). One method of recruitment (volunteer) but screening takes place and sample are recruited from target population therefore has been assigned score of somewhat likely. The tool does not take into consideration volunteer samples/recruitment from diagnosed patients with migraine etc., which then proceed to screening.
3. Not likely –
4. Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 80% - 100% agreement From 106 and exclusion (flow chart) all 44 agreed to participate=100%,
- 60-79% agreement
- Less than 60% agreement
- Not applicable
- Can't tell –
- Scoring – Q1 is 2 & Q2 is 1 = strong

RATE THIS SECTION	STRONG	MODERATE	WEAK
SEE DICTIONARY	<u>1</u>	2	3

C.2 STUDY DESIGN

Indicate the study design

1. Randomized controlled trial – (two group pre + post) experimental design two groups two interventions and an additional clinical control sample receiving standard internet treatment. Authors have described this as a RCT, even though method of allocation of random assignment has not been discussed. Therefore, will go with RCT which authors have submitted to journal.
2. Controlled clinical trial
3. Cohort analytical
4. Case-control
 5. Cohort (one group pre + post (before and after)
 6. Interrupted time series
 7. Other specify
 8. Can't tell

Was the study described as randomized? If NO, go to component C.

NO	<u>YES</u>
	Has mentioned randomized

If yes, was the method of randomization described? (See dictionary)

<u>NO</u>	YES
Does not described method of allocation	

If yes, was the method appropriate? (See dictionary) n/a

NO	YES
----	-----

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RATE THIS SECTION	STRONG	MODERATE	WEAK
SEE DICTIONARY	<u>1</u>	2	3

C.3 CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1. Yes –
2. No - table presented but has not been discussed test carried out at base-line – therefore moderate
3. Can't tell

The following are examples of confounders:

1. Race
2. Sex
3. Marital status/family
4. Age
5. SES (income or class)
6. Education
7. Health status
8. Pre-intervention score on outcome measure

(Q2) IF yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1. 80 – 100% (most)
2. 60-79% (some)
3. Less than 60% (few or none)
4. Can't Tell

Should be strong but method of matching etc. not been discussed therefore is moderate

RATE THIS SECTION	STRONG	MODERATE	WEAK
SEE DICTIONARY	1	<u>2</u>	3

C.4 BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1. Yes
2. No
3. Can't tell – has not been discussed – blinding has not been described.

(Q2) Were the study participants aware of the research question?

1. Yes
2. No
3. Can't tell – has not been discussed or indicated.

Q1 is 3 & Q2 is 3 scoring is moderate As blinding wasn't mentioned doesn't that make it weak?

Discussion – no as rating gives this a moderate rating.

RATE THIS SECTION	STRONG	MODERATE	WEAK
SEE DICTIONARY	1	<u>2</u>	3

C.5 DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1. Yes – validity has been discussed in detail for measurements which sit outside headache self-report
2. No

3. Can't tell

(Q2) Were data collection tools shown to be reliable?

1. Yes – as stated above

2. No

3. Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
SEE DICTIONARY	<u>1</u>	2	3

C.6 WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1. Yes – have been described and discussed

2. No

3. Can't tell

4. Not applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1. 80-100%

2. 60-79% - 34/44 COMPLETE (DO 23%)

3. Less than 60%

4. Can't tell

5. Not Applicable (i.e., Retrospective case-control)

Q2 = 2 therefore moderate scoring is assigned to this section

RATE THIS SECTION	STRONG	MODERATE	WEAK
SEE DICTIONARY	1	<u>2</u>	3

C.7 INTERVENTION

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1. 80-100% For this study exposure of interest is self-help plus telephone 55% and without telephone [all participants received treatment – a) self-help plus telephone 55% b) self-help only 45%.

2. 60-79%

3. Less than 60%

4. Can't tell

(Q2) Was the consistency of the intervention measured?

1. Yes

2. No – no details of fidelity assessments, and no checking of the email/telephone contact by independent raters, however also little detail about who was conducting the intervention i.e. supervision etc.

3. Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4. Yes

5. No
6. Can't tell

C.8 ANALYSES

(Q1) Indicate the unit of allocation (circle one)

Community organisation/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

Community organisation/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1. Yes
2. No
3. Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1. Yes
2. No even though all treated; drop-outs haven't been considered in analysis
3. Can't tell

C.9 GLOBAL RATING FOR THIS PAPER

1. **STRONG** Four strong points with no weak
2. **MODERATE** Less than four Strong ratings and 1 weak rating
3. **WEAK** Two or more weak ratings

A	SELECTON BIAS	<u>STRONG</u>	MODERATE	WEAK	
B	STUDY DESGIN	<u>1</u> <u>STRONG</u>	2 MODERATE	3 WEAK	
C	CONFOUNDERS	<u>1</u> STRONG	2 <u>MODERATE</u>	3 WEAK	
D	BLINDING	1 STRONG	<u>2</u> <u>MODERATE</u>	3 WEAK	
E	DATA COLLECTION METHOD	1 <u>STRONG</u>	<u>2</u> MODERATE	3 WEAK	
F	WITHDRAWALS AND DROPPUTS	<u>1</u> STRONG	2 <u>MODERATE</u>	3 WEAK	
		1	<u>2</u>	3	NOT APPLICA BLE

C.10 REVIEWERS

Is there a discrepancy between two reviewers?

YES

NO

If yes, indicate reason for discrepancy:

1. Oversight
2. Difference in interpretation of criteria

Difference in interpretation of study

C.11 FINAL OUTCOME

1. STRONG
2. MODERATE X
3. WEAK

Appendix F

Reviewer's correspondence and agreement

To:

Devinder2.Rana [Devinder2.Rana@live.uwe.ac.uk]

Attachments:

DR papers DB Quality Ax.zip (1 MB)

Hi Devinder,

Please find attached your 10 articles I assessed for quality as a second reviewer. I know you said Martin was out, but if you want me to look at that one too I only have the data extraction sheet/Quality sheet and not the pdf/paper itself to refer to, if you send me that I'll look at it too.

If you want to discuss any let me know - hope all is going well. All looks fine.

Best wishes

Debbie

Discrepancies were agreed on the phone and have been noted on the quality/data extraction sheets with the final rating which reflects discussion and agreement reached.

Appendix G

Participant selection, head diagnosis, recruitment.

	Diagnosis	Sample size Eligible for study /completed treatment	Mean/age range Gender F/M %	Participant recruitment
1	Yes ICHD-1 (TTH/M /Com.) 6 mnt. or >	44 30	40.3 (18-59) 82/18	Newspaper article regional papers and webpage for project Swedish - volunteers
2	Yes Screen Que. (AO) First stage screening first author and registered nurse. Additional screening University Health centre staff/medical records (TTH) Mean HA 60 or > (2 wk.)	40 39	19.7(n.s.) 85/15	University – local Student population selected and recruited by screening questionnaire 17 undergrad psychology course sections – “Even though a student population was selected, rigid selection criteria were devised to ensure that selected subjects were as clinically representative of adult outpatients as possible” – volunteers 1,221 questionnaires completed/106 frequent, intense, persistent symptoms of TTH 106 – 18 point telephone screening interview (inclusion/exclusion) Further screening small groups first author and registered nurse Questionable subject refer to university health centre for additional diagnostic evaluation 43/106 excluded from above steps. University health centre staff check med records and ensure students meet with diagnostic criteria based of HA symptoms, self-monitored 2w evidence mean HA ACTIVITY SCORE = TO OR GREATER THAN 60 TO BE INCLUDED. USA
3	Yes ICHD-1 (TTH/M) n/s	51 38	35.2(18-50) 89/11	Clinical – local GP referral 51 primary headache disordered patient recruited d form an outpatient university headache clinic mountain western region of US INCLUSION – IHS
4	Yes The Headache Symptom Questionnaire	139 86	41.2 (18 >) 79/21	Clinical web-based Internet – head related electronic newspapers national Common-internet-based promotion channels. Hyperlinks exchanges with other headache and chronic pain consumer-oriented websites, classified ads placed

	(HSQ; Arena, Blanchard, Andrasik & Dudek, 1982) - based on Ad Hoc Committee (M/TTH/Com.) 12 mnt. or >				on health and wellness sites, registration with major search engines, notices posted to headache-related newsgroups Formal diagnosis for a year from GP – volunteers
5	Yes Project evaluator & neurologist (TTH) n/s	41 36	32.3 (19-55) 80/20	University research centre clinic presented for treatment-clinic referral From both project neurologist and a psychologist evaluator –diagnostic agreement	
6	Yes ICHD-1(M) 12 mnt. or >	129 99	44(18-65) 87/13	Clinic/research centre local The study was conducted out in cooperation with the Dutch Society of Headache Patients and profited from its support website for recruitment. To reach a broad population; members of the organization were invited, local headache specialist could refer patients and new Papers magazines and websites of the research centres were used. Migraine patients interested in BT which was provided by experienced fellow patients were asked to respond living in or around research centres Rotterdam and Utrecht Amsterdam Volunteers/clinical referral	
7	Yes ICHD-1 (M) 4 x or > per mnt.	25 21	42(22-65) 95/5	Clinical/community GP referral & local media	
8	Yes ICHD-1 (TTH) n/s	45 44	18.9 (18-22) 18-22 86/14	University local 2,500 undergraduate psychology students completed screening questionnaire then proceed onto screening conducted by graduate students trained in IHS; 2 week baseline ha recording	
9	Yes Que. based on Ad Hoc Committee on Classification of HA (1962) by experienced clinical psychologist (M) n/s	32 29	35.6 (19-59) 83/17	Clinic / GP referral/self-referral Netherland Society Migraine Patients – national	

10	Yes ICHD-11 (M/TTH/Com.) 3 pain days per mnt. >/ HA last 6 mnt.	40 31	42.7 (19 >) 82/18	Clinic/community GP referral/Neurologist referral from Kilgo Headache Clinic/newspaper local and national
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Key code:

Diagnosis Yes/No; Diagnosis criteria Published (Internal Headache Society (IHS)/ Authors own (AO); Head pain type:

Tension-type head pain (TTH); Migraine (M); Combined (TTH & M). Head Pain duration

Appendix H

Summary of quality rating for included studies.

	1	2	3	4	5	6	7	8	9	10
(A) Selection bias	S	M	M	M	M	S	S	M	M	M
(B) Study design	S	S	S	S	M	S	M	S	M	S
(C) Confounders	M	S	S	S	S	S	N/A	S	S	S
(D) Blinding	M	M	M	M	M	M	M	M	M	M
(E) Data collection methods	S	S	S	S	S	S	S	S	W	S
(F) Withdrawal and dropouts	M	S	M	M	S	S	S	S	S	S
<u>Overall Global rating</u>	M	S	M	M	M	S	M	S	M	S

Strong: S

Moderate: M

Weak: W

Not applicable: N/A

Appendix I

HP mean percentage calculations

		HA/HI	HF/H D	TD	ED	PI/RI	MI	MF	MD	P/H A	HF D	SD
1	SHT SH	-5% -3% -52%	1% -11%	-29% 33%		-5% 15%				-4% - 13%		Little improvement Sig Int. Duration (F=7.16, P =.012) TD SHT sig decreased duration (P<.05); increase SH not significant Yes Reduction HI (CCS) (F=4.8, P=.064)
2	EMGD: EMGI: EMGNC: RO: <u>Pre-1.5MFU</u> EMGD: EMGI: EMGNC: RO:	-79 -62 -74 -7 -76 -69 -81 -4	-68 -40 -53 -20 -57 -55 -55 -25	-80 -48 -61 -6 -71 -58 -64 -5	-50 -36 -40 -3 -50 -36 -43 -7	-70 -52 -45 -6 80 -60 -45 3	-48 -34 -28 0 -36 -45 -31 0					Yes x6 at Post & FUM F= Range 3.05 – 9.24 p=.05 EMGD X6 EMGI X4 EMGNC X2 CT RO
3	<u>Pre-1MFU</u> (8wks) SET IOT NTC	-7 17 36	0 -9 -5				-12 -7 -6					No Study not powered to detect HA differences Reasons in paper i.e., motivation etc.
4	<u>Pre-post</u> PMR/CT WLC	-42% -14%										Yes significant reduction pre to post F(1,84)=112.99, p<.0001
5	<u>Pre-post</u> CBT DRUG	-56% -27%				-32% -28%					- 67% - 56%	Yes Significantly larger reduction in HA with CBT than drug [Treatment group x treatment phase interaction] F (3, 32) =2.93, p, <.05.
6	<u>Pre-post</u> BT WLC Total		-21% -9% -16%									No ES -0.29 effect size small therefore supporting non- significant trend (P=0.07)

HP Acronyms

Mean score difference unless otherwise stated

HA = Headache activity

HF= Headache frequency

HFD= Headache free days

TD= Total duration

ED= Elevated duration

PI=Peak Intensity

MI= Mean Intensity

SD= Sig Diff

ES Effect size

Pre.T = Pre Treatment

Pos.T= Post Treatment

PHA Peak headache

CT= Compare to

FUM = Follow up month

Psychological Distress Table.

Depression

N	Int.	Intervention			FU	% mean difference	Type	Control			FU	FU	% mean difference	Statistical significance
		N	Pre	Post				N	Pre	Post				
1	SHT SH CS (SH)	15 9 8	5.7 (4.3) 6.8(2.5)	4.5(3.9) 4.9(3.3)		-21% -28%							Decreased both groups: Sig main effect HAD (F1,22=4.53,P=.045) pre-to-post but interaction not sig.	
2	EMGI EMGD EMDN C	10 10 9					RO							
3														
4	PMR/C SCT/A T/PMR /LiBio	39	15.8(11.2)	12.4(10.7)		-22%	WL		13.9 (9.5)	14.3 (12.1)		3%	Condition x time significance F(1,84)=2.63, p=.11; not reach stat sig level pre-to-post	
5	CBT	19	9.26(5.41)	5.16(4.65)		-44%	Amitrip		7.69 (5.88)	5.56 (5.85)		-28%	MANNOVA Main effect for treatment phase F (3, 31) =7.32, P<.001 indicating sig reduction in psychological symptoms with treatment.	

2	CS (SH) EMG I EMG D EMD NC	10 10 9	4.1 5.7 5.6	4.8 5.2 4.3	5.4 4.1 3.9	17% -9% -23%	RO	10	5.5	5.9	5.1	7%	Across group's non-sig: equated to exposure to stress: measure events as opposed to actual change in stress. No test pre-to-post NOT RELEVANT
3													
4	PMR /CSC T/AT /PM R/Li Bio	39					WL						
5	CBT	19					Amit rip						
6													
7	Self beh	21	86.4(29.8)	64.3(24.8)	- 26% Th								Significantly improved F(3,18)=4.82, P<.05, N2=0.49 (Combined anxiety, stress and depression)
8	EMG	29					CG						

Appendix L

Coping outcomes tables

Control

N	Int.	Intervention			Control						Statistical significance				
		N	Pre	Post	FU	% mean difference	Type	N	Pre	Post		FU	FU	% mean difference	
1	SHT	15													
	SH	9													
	CS (SH)	8													
2	EMGI	10	30.1	32.3	29.2	7%	RO		31.7	32.3	33.0		2%	HLC: No discussion on HLC outcome and tests Self-control frontal EMG: Significant pre-to-post 3 biofeedback with pre-treatment data acting as covariate: sig – F (2, 25) =27.94, P<.0001. Self-control sig: F	
	EMGD	10	31.3	30.8	31.3	-2%									
	EMDNC	9	32.8	30.7	29.2	-5%									
	<u>Sel. Cont</u>														
	EMGI	10	-15.2	-17.9	-16.0	18%	RO		-30.4	-27.7	-27.7		-9%		
	EMGD	10	-36.2	-34.2	-35.8	-6%									
EMDNC	9	-29.7	-29.2	-25.7	-12%										

8	EMG PMR	30	3.3(.7))	2.8(.7)				-15%	CG	14	3.2(.6)	2.9(.8))	-9%	Within group t 4.5, P<.001 treatment group sig increase se pre to post (n/s) 2 pre-post x2 group repeated ANNOV SIG PRE-POST MAIN EFFECT F[1,42]=15.99, P<.001 – INDICATING TREAT N CONTROL REPORTED GREATER SE (LOWER HSES SCORE)
9														
10	RT SCT	12 15												
11	CR/CC CC/CR		115.4 0(24. 19)	138.02(23.52)	142.46 (21.40)	142 .41(20. 26)	20%							F(1,30)=44.27, p=<.001, d=1.16 post F(1,15)=34.547, P<.001, D=1.34 FU

Coping

No.	Int.	Intervention		FU	% mean difference	Control				FU	F	% mean difference	Statistical significance
		N	Pre			Post	Type	N	Pre				
1	SH T SH	15 9	Divert attention 7.4(3.6)	8.6(6.7)	16%								CSQ: some improvements- sig main effect time “reinterpreting pain sensation” (F1,22=11.2, p.029); sig reductions- “catastrophizing” main effect of time- (F1,22=7.7,P=.011); sig interaction effect “ignore pain sensation” (F1,22=5.3, P=.031) Bonferroni post hoc sig reduction SHT and between-group diff in favour of SHT. Sig interaction “coping self-statements” (F1,22=5.6,P=.027)
			Reinter pretatio n pain sensatio n 3.8(5.1) 2.1(2.6)	6.1(6.1) 4.6(4.6) 14.7(5.2) 18.7(5.5)	61% 119% -17%								
			Coping 17.7(6.4) 16.3(5.2)	13.7(3.3) 18.2(7.0)	-19% 6%								
			Ignore pain sensatio ns)	8.8(5.5) 15.4(10.9)	-3% 11%								

Correlation head pain and depression/anxiety/stress and or control/self-efficacy/coping

1	Internet SHT/SH COMBINED	<u>Yes sig depression and HI</u>	Sig ass between change scores HDI and clinical sig changes in HDI Exception n=1 deterioration HI but improved HDI	R=-.56, p=.007
2	Biofeedback university	<u>Yes anxiety and HD/H intensity</u> No of stress events sig related to follow-up elevated duration	Trait anxiety was positively associated with improvement on post treatment elevated duration and post treatment mean intensity	
3	SET video: self-help	HLO-NO No	Higher SE but no HA but no prime focus of study – severe ha problems	
4	Internet- PMR/LIM BIO DEV	Not supported anxiety and dep improve stats sig from treatment – not explore relationship.		
5	CBT VS. DRUG	<u>Not explorer rel. but same direction in favour of CBT</u>	Sig larger reduction somatic complaints CBT T(18)=3.3,P<.001 compare to drug t(16)=.39, p<.05 and only CBT change HLOC – HA within their control at end of treatment compared to beginning F(1,33)6.99,P<.05 – LARGER DECREASES IN hloc CBT than drug. 56% HI CBT headache; drug 27% reduction headache free days: same direction but not explore relationship.	
6	Home beh lay trainers Merelle	Not explore in detail but state that. High frequency group showed sig improvement in disability from baseline and follow-up 27.4 to22.6 p=.04;		

		<p>Migraine specific quality of life changed overtime sig linear trend $f(1, 92) = 10.7$. $p = .002$ but physical and mental health status not change</p> <p>Use triptans decreased sig 3.60 to 3.32 post BT and to 2.68 fu</p>	
7	Self-Admin Beh post Nicholson	<p>Dep, anxiety, pain related anxiety improved only pain related anxiety significantly improved $n^2 = 0.40$; HMSE sig improved $n^2 = 0.38$</p> <p>Correlation; Changed in ha frequency correlation changed in other variables showed sig improvement baseline /re to post. Stress and HA freq 0.48, $p < .001$; pass and HA 0.44 $p < .001$ (POSTIVE CORRL HA DECREASE AND STRESS/PASS) Negative correlation HMSE: se increase, HA DECREASED -0.52 $P < .001$</p>	
8	Relax/bio clinic	<p>Sig positive relationship se end of treatment and HA activity improvement scores end of treatment and post for treated participants. Increase in SE (DECREASE SE SCORE) during treatment was related to subsequent improvement in HA activity during post treatment weeks one ($r = -.41$, $p < .05$) and two ($r = -.37$, $p < .05$) but were unrelated to concurrent improvement suggesting CHANGES IN SE PRECEDED CHANGE IN HA ACTIVITY No sig correlation improvement ha activity and change EMG activity for any muscle group – decrease in muscle tension were unrelated to headache improvement</p>	
9	RT SCT	<p>Efficacy of relaxation in coping with major stressful life events and preservations of relaxation skill accounted for</p>	

		<p>73% of variance in long-term RT improvement scores $r=.85$</p> <p>SCT preservation of skills and self-motivation generated by patients to preserved these skills, two factors accounted for 91% variance in long term SCT improvement scores $r=.95$ FREQUENCY NOT SO MUCH DURATION AND INTENSITY.</p> <p>Si diff pre to post HA frequency and BDI ANXIETY SE but no correlation conducted</p>		
10	Cbt clinic			

Appendix N

Head pain clinical significant improvement table

Study	Clinical improvement
1	HA: Clinical significance (50% decrease HI) reach criteria clinical improvement: Yes (SH 23%; SHT 29%)
2	HA: Clinical significance (50% decrease HI) reach criteria clinical improvement: Yes (80% in all 3 biofeedback groups at both assessment points) Recording group: No
3	HA: Clinical significance (50% decrease HI) yes reach criteria clinical improvement: N
4	Clinical significance: reached by yes 38.5% intervention group; WLC 6.4% (50% or greater reduction in HI)
5	Clinical significance: yes reached by 37% CBT group; 18% AHLC group ⁽¹²⁾
6	Clinical significance: 35% BT improved; WLC 0% BUT 19% clinically changed.
7	Clinical significance: 62% had at least 50% reduction
8	Clinical significance: 52% of treated group clinically improved; 0% in RO
9	n/s
10	29.6% treatment clinically improved; modest responders (25% to 49%) 40.7% completers; greater than wait list control group [$\chi^2 = 4.41, P=.042$]

Group allocation, attrition, follow-up table

1	SD: Pre – post ERMD CG: Clinical control sample AD: Yes	44 WB-SH&T 55% (24) WB-SH: 45% (20)	Post: 68% (30/44) WB- SHT&T (17) SH (13)	No	BGC: Yes BGD: No C/DO DIFF: No
2	SD: Pre – post ERMD CG: Yes AD: Yes	39 Bio/EMG”I” 26%(10) Bio/EMG”NC” 23% (9) Bio/EMG”D” 26% (10) RG/Que. 26% (10)	Post n/s 1.5 MFU 97%	No	BGC: Yes BGD: N/S C/DO DIFF: N/S
3	SD: CCT CG: WLC AD: Yes	51 SET 37% (14) IOT 34% (13) WLC 29% (11)	Post n/s 1 MFU 75% 38/51 SET (14) IOT (13) WLC (11)	No	BGC: Yes BGD: N/S C/DO DIFF: N/S
4	RCT CG: WLC (Ques.) AD: Yes	139 WB-PMR/CT/BM 28% (39) WLC (Ques.) 35% (47)-allocation shown after drop-out	Post-T 62% 3 MFU 35%	Yes	BGC: Yes BGD: No Stat. Diff. C/DO DIFF: No Stat. Diff.
5	PRT CG: No (drug group comparison)	49 CBT 49% (20) Drug 51% (21)	Post N/S 3 MFU 88%	Yes	BGC: Yes BGD: No Stat. Diff. C/DO DIFF: No Stat. Diff.
6	SD: RCT	127	Post 85%	Yes	BGC: Yes

	CG: WLC (CAU) AD: Yes	Group Ho.- BT 47% (60) WLC (UC) 53% (67)	6 MFU 75%		BGD: No Stat. Diff. C/DO DIFF: N/S
7	SD: Pre-post ERMD CG: No (OT) AD: Yes	25 Ho. SA/Beh. 100% (25)	Post 84% 2 MFU N/S	No	BCG: N/A BGD: N/A C/DO DIFF: N/S
8	SD: CCT CG: Yes (AO) AD: Yes	45 PMRT/EMG.Bio-f. 68% (30) PMRT 32% (14)	Post 96%	No	BCG: Yes BGD: Yes C/DO DIFF: N/S
9	SD: Pre-post RM/CA CG: No AD: Yes	32 Relax Train. 50% (16) Str. Cop. Train. 50% (16)	Post 91% 36 MFU 75%	No	BCG: Yes (Pre-post) BGD: No C/DO DIFF: No
10	RCT CG: (Delay WLC) AD: Yes	34 Re. Cog-Cop. (44%) 15 Cog. Cop. Re. (56%) 19	Post 97% 1 MFU 12 MFU	Yes	BCG: Yes BGD: No C/DO DIFF: No

Coping assessments

(8) Used two assessments – (Headache Specific Locus of Control Scale, [HSLC]) (Martin, Holroyd, & Penzien, 1990); and (Electromyography [EMG]) (Lippold, 1967). (6,7,8) also employed (HSLC, Martin et al., 1990);(6) identified the questionnaire as attaining good reliability in the sample (Mérelle, Sorbi, van Doornen, & Passchier, 2008) and excellent internal consistency of sub-scales Chronbach $\alpha = 0.91$; (7) stated strong validity and (8) did not discuss the psychometric properties of the HSCL. Studies (2, 8) used (EMG, Lippold, 1967) and both discussed high reliability and validity. (5) Employed the (Head Locus of Control [HLOC]) (authors own), which was modified version of the (Multi-dimensional Health Locus of Control [MHLOC]) (K.A. Wallston, B.S. Wallston, & DeVellis, 1978), which had high reliability and validity.

Coping. 2 studies in the review (1, 10) assessed coping. (1) Was assessed by the (Coping Strategy Questionnaire [CSQ]) (Rosenstiel & Keefe, 1983) which was reported to have satisfactory psychometric properties Chronbach $\alpha = .70 - .80$. (10) Employed (ELC, authors own) and consequently had no discussion on the psychometric properties.

Self-efficacy (H-SE). 50% of studies (n=5; 3, 6, 7, 8, 10) assessed H-SE, of which, 4 studies used various versions of the Headache Management Self-Efficacy Scale. (3) Used the (Headache Management Self Efficacy Scale [HMES]) (French et al., 2000) which was discussed as having acceptable internal consistency – Chronbach $\alpha .92$ (time 1) - $.95$ (time 2) and acceptable temporal consistency $r=.84$. 6, (10) also used the (HMSE; French et al., 2000). (6, 10) identified the psychometric properties of the sub-scales attaining a range between good to excellent internal consistency - Chronbach $\alpha = 0.90$ of sub-scales, and (6) additionally discussed good reliability. (7) Employed stated strong internal consistency and validity. (8) Employed the (Headache Self-Efficacy Scale

[HSES] (Martin, Holroyd, & Rocklike, 1993) and failed to discuss the psychometric properties of the HSES. (Refer to Figure 4).

Study selection

The subsequent exclusion of duplicate abstracts (n=8,413 abstracts); secondary sources (n=192 abstracts); abstracts which were not written in English (n=28 abstracts); and the remaining (n=7,043 abstracts), which did not meet with the inclusion criteria. A further breakdown of the n=7,043 excluded abstracts show that, n=2009 had no intervention; n=4479 had head pain data which was not translated into a head pain index, and a further n=24 abstracts, did not assess psychological distress (depression/stress/anxiety) and or, coping (incl. control and self-efficacy); n=120 examined head pain which was not, migraine/TTH/combined; and n=59 were menstrual related/geriatric migraine. This resulted in, n=241 abstracts, which were subject to blind peer review.

Abstracts were excluded if the psychotherapeutic intervention was not underpinned by cognitive/behavioural/C&b theory (n=5); cognitive/behavioural/C&b based psychological intervention (n=7); relevant secondary outcomes were not assessed – (psychological distress and or coping) (n=8); the design was a case-study (n=4). This resulted in n=212 papers, which were retrieved for double-blind peer review.

From the n=212 articles, n=200 papers were subsequently excluded by the two reviewers. A breakdown shows that, n=25 were not written in the English language; n=8 papers did not exclusively focus on the diagnosis, of migraine/TTH/combined; n=59 articles did not assess a secondary outcome (psychological distress: depression/stress/anxiety, and or, coping: incl. control/self-efficacy), at Pre-/I and Po/I; n=21 articles did not have cognitive/behavioural/C&b based interventions; n=8 articles were excluded as duplicates; n=2 were excluded as the study design was a case study. A larger number of studies were based on biofeedback; consequently n=52 were excluded the biofeedback outcome was only reported as a electromyography [EMG] reading; n=20 did not have the relevant outcome data; i.e., head pain not calculated according to at least one of the following head pain indices (Activity/Duration/Frequency/Intensity),

n=3 articles were excluded, as the sample consisted of psychiatric participants/geriatric/menstrual related migraine and n=2 studies (Martin, Nathan, Milech, & van Keppel, 1989; Sharma, Mishra, & Balodhi, 1990) attained 2 or \geq weak ratings, during the quality assessment process, based on the EPHPP (2007) – Appendix H quality assessment for excluded papers.

Consequently, this review comprised of n=12 articles. Two studies (Mérelle, Sorbi, van Doorenen, & Passchier, 2007; Mérelle, Sorbi, van Dooren, & Passcheir, 2008) were merged, as well as the two studies conducted by Sorbi and Tellegen (1988), and Sorbi, Tellegen and Du Long (1989). Consequently, this resulted in n=10 studies (13 Cbt trials) which were included in the final review, agreed by the two reviewers (blind review) (figure 2).

Physical therapies [excluded]

“Physical-therapies” were excluded, these being - aerobic exercise (Babyak et al., 2000; Blumenthal et al., 1999; Dittrich et al., 2008); spinal manipulation (Astin & Ernst, 2002); hyperbaric oxygen (D.E. Myers & R.A. Myers, 1995; Wilson, Foresman, Gamber, & Wright, 1998). Alternate medication was also excluded, based on previous studies (i.e., Blanchard, Andrasik, Ahles, Teders, & O’Keefe, 1980), which included, homeopathy (Jacob, Turner, Szekly, & Eidelman, 1998) and acupuncture (Gendolla, Pageler, & Diener, 1999; Melchart, Linde, & Fischer, 2001). Hypnosis and future imagery (Gauthier, Lacroix, Cote, Doyon, & Drolet, 1985) are interventions which are not predominately based on cognitive, and or, behavioural principles, (McGrath, 1999) which were consequently also excluded.

Appendix S

Diagnosis breakdown

30% of studies (n=3; 1,4,10) had a sample which comprised of all of the following - migraine/TTH/combined; 30% (n=3; 2,5,8) consisted of a sample which were diagnosed with TTH; 30% (n=3; 6,7,9) of studies consisted of a sample which were diagnosed with migraine, and 10% (n=1; 3) of studies comprised of migraine and TTH participants.

Head pain duration (HPD). 60% of studies, specified a minimum duration period of HP (n=6; 1,2,4,6,7,10), of which studies (4,6) had a 12-m or \geq duration of head pain, and (1) had a shorter period of, 6m or \geq head pain. 3 studies (2,7,10) specified duration in relation to number of days - HP score of 60 or \geq , over 2-wks (2); 4-d \geq /per-month (7); and 3-d or \geq /6-months or \geq (10). 40% of studies (n=4; 3,5,8,9) failed to discuss a minimum HPD criteria, of which, 2 studies (3,5) based HPD duration according to the IHS (1989) criteria for diagnosis and screening of head pain disorder.

Appendix T

Sub-questions

The following sub-questions were identified: a). Are Cbt's effective in reducing HP, and does the effectiveness vary according to the type of HP being assessed (i.e. Activity/Duration/Frequency/Intensity)? b). Does the mode of delivery of C&bt's, impact on post-intervention (Po/I) head pain outcomes? c). Which Cbt based interventions meet with the criteria of significant clinical improvement of head pain? d). Are Cbt's effective in improving psychological distress, and or, coping? e). Is there an association between, head pain scores (decrease) and psychological distress (decrease) and or coping (increase) at Po/I?

Annex A

Time plan – flow chart

