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Living with chronic headaches: A qualitative study from an outpatient pain clinic in Norway

Jill Brook Hervik^a, Eva B. Foss^a, Trine Stub^{b,*}

^a Department of Anaesthesia, Pain Clinic, Vestfold Hospital Trust, 3116, Tønsberg, Norway

^b UiT The Arctic University of Norway National Research Center in Complementary and Alternative Medicine (NAFKAM), Faculty of Health Sciences, Department of Community Medicine, Hansine Hansens veg 19, 9019 Tromsø, Norway

ARTICLE INFO

Keywords:

Chronic headache
Trauma
Pain
Quality of life
Emotional and behavioural changes
Embodiment

ABSTRACT

Background: Although headache is considered a frequently experienced type of pain, the challenges, experiences, and perceptions of people suffering from chronic headaches are poorly understood. The aim of this study was to gain subjective information regarding these aspects in daily life, in order to answer the research question “What is life like with a chronic headache?”

Methodology: Semi-structured, in-depth interviews were conducted with 16 patients who suffered from chronic headaches. Five main domains were explored: *emotions related to headaches; trauma/stressful events; behavioural changes, relationships, and coping mechanisms.*

Analysis and interpretation: Participants reported that pain restricted their lives in many ways, including not being able to work, loss of status, identity, freedom, intimate relationships and friends. The majority believed that psychological and/or physiological trauma was the reason for their headaches. New information that emerged from this study was how common life events not usually considered major traumas, initiated and maintained symptoms. Shame and feelings of stigmatization appeared to be strongly associated with chronic pain, leading to a scenario where thriving, contentment and enjoyment were often lacking.

Main results: This study provided an in-depth understanding of how chronic headache adversely affects the lives of sufferers. Chronic headaches restrict sufferers’ lives, resulting in emotional and behavioural changes and a high level of disability. The complexity of chronic headaches in clinical practice is hugely underestimated, and poorly understood by society in general.

Introduction

Although headache is considered a frequently experienced type of pain, chronic headaches, and intractable migraine can lead to a serious reduction in function and quality of life.¹ The World Health Organization (WHO) has highlighted the financial burden that headache disorders have on economies at all levels, while at the same time emphasizing the lack of importance generally attributed to these conditions.²

The Global Burden of Disease studies established tension-type headache as the second most prevalent condition in the world (22%) and migraine third (15%), trailing only dental caries in the numbers of people affected.³ Other types of chronic headaches include post-traumatic headaches, daily persistent headaches, and hemicrania continua.

The international headache society defines chronic headache as a headache that occurs for at least 15 days or more a month, for longer than three months.⁴ In some cases, patients with chronic headaches suffer headaches of such persistence that it becomes impossible to distinguish individual episodes of pain.⁵ The escalation from episodic to chronic headache is associated with a high degree of disability, affecting sufferers, their families, and employment situations. Economic consequences can be both personal and social.⁶ There is evidence indicating that depression, anxiety, poor sleep, and stress are potential prognostic factors for unfavourable preventative treatment outcomes of chronic headache disorders.⁷

Primary headache disorders have no clear underlying cause, symptoms include recurrent or persistent head pain.⁸ Tension-type headache is the most prevalent primary headache disorder. Chronic tension-type

Abbreviations: GP, General practitioner; HUNT, Nord-Trøndelag health study; ID, Identifier numbers; WHO, World Health Organization.

* Corresponding author.

E-mail address: trine.stub@uit.no (T. Stub).

<https://doi.org/10.1016/j.explore.2023.01.004>

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headache causes significant disability and often requires medical attention. Diagnosis and treatment dilemmas present when tension-type headaches and migraine overlap.

The Nord-Trøndelag Health Study (HUNT) performed in 2006–2008 (HUNT3) and 2017–2019 (HUNT4), demonstrated headache trends in Norway.⁹ A comparison of HUNT 3 and HUNT4 time periods showed an increase in tension-type headache (20.7% vs. 15.9%, $p < 0.001$). Female sex, the occurrence of chronic musculoskeletal complaints, and a high depression or anxiety score at baseline doubled the risk of headache incidence in these surveys. A female-dominated gender ratio regarding chronic headaches was also demonstrated in a worldwide review of the general population from 1977 to 96 in which included 75,000 people were included.¹⁰

Although headache is a frequently experienced type of pain, chronic headache can lead to a serious reduction in function and quality of life. The International Headache Society⁶ has introduced guidelines for the organization of headache service and management, however, there is no single standard of care for patients presenting with primary chronic headache symptoms. Treatment is often initiated by patients themselves, without medical consultation.¹¹ Guideline recommendations for self-medication are a standard dose combination of paracetamol, aspirin, and caffeine; or monotherapy with ibuprofen, naratriptan, or paracetamol as first-line therapy.¹²

Although there has been significant improvement in the management of primary headaches, inadequate response to medications, estimating dosage, and adverse effects create treatment challenges. Symptoms are largely invisible, chronic headache is often considered an accepted part of people's lives. In women, headache is often trivialized as an inevitable consequence of fluctuating hormones and life changes. Such discrimination can lead to feelings of stigmatization and suffering in silence.

Chronic headache presents a complex situation, to try to understand some aspects of this condition, this study aimed to answer the research question *what is life like with a chronic headache?*

Theory

The impact of stressful life events on health

A 10-year observational study of 1038 participants reported that stressful life events were associated with negative changes in self-rated physical and psychological health.¹³ Research has suggested that stress is related to an increase in chronic daily headache¹ and that daily headache is more likely in divorced, widowed, or separated people.¹³ In order to gain a better understanding of the complicated relationships between life events, ageing, health, and human development *the life course approach*¹⁴ is a useful tool. The approach provides an interdisciplinary framework to understand health, human development, and ageing. Bringing together psychological, cognitive, and biological research related to development from conception to death. The way in which these aspects influence health and disease in adult life may go some way to explaining social inequalities in adult health and mortality. The life course approach has much in common with the theory of Habitus developed by the French sociologist Pierre Bourdieu¹⁵ who referred to Habitus as the embodiment of history. *Embodiment* describes how extrinsic factors experienced at different life stages can become part of an individual's body and soul.

Qualitative research methods have been used to analyse what effect migraine has on work, leisure, social, and family life.^{16, 17} There are fewer studies regarding only chronic headaches. One systematic review and synthesis of qualitative literature,¹⁸ investigating the lived experience of chronic headaches, included 86 studies. Three main themes emerged when results were analysed, headache as a driver of behaviour, the spectre of headache, and strained relationships. Personal experience of illness relating to emotions, relationships, and aspirations are aspects not easily measured by questionnaires and therefore not suited to quantitative research.^{19, 20} By applying qualitative methods in this

study, we aimed to answer the research question “what is life like with a chronic headache?” The purpose of this study was to explore the experiences and perspectives of a group of Norwegians suffering from chronic headaches. A literature search revealed that there are no qualitative studies to date that have focused specifically on Norwegians with chronic headaches.

Aim

To explore the lives and experiences of headache sufferers. The main aim of this study was to gain subjective information regarding the lives of chronic headache sufferers. Secondary outcome measures included obtaining information and examples of behaviour in response to having a chronic illness. In addition, we sought clarification of the thoughts and feelings of study participants, interpretation of participants' experiences related to their headaches, and explanations for their behaviour in different situations.

Methods

Anonymity

Pseudonyms and randomized identifier numbers (ID) to protect and ensure the anonymity of the participants were used.

Qualitative studies

Subjective information from patients is useful in order to understand how symptoms affect daily life,²¹ providing a base for the facilitation of actions, including identifying risk factors, prevention techniques, treatment strategies, and improving physical and emotional function levels. Although qualitative data can be useful in all types of clinical settings, it is especially important in the area of pain management, where understanding patient experiences is essential and often unexpected, especially in those with chronic symptoms. Qualitative research has the potential to provide insight into what aspects of health, illness, and function are important to patients. Qualitative data can be useful when planning quantitative research, especially when defining aims and outcome measures.²²

Study and setting

This study was conducted as a focused ethnographic study¹⁹ where the investigators wanted to identify information regarding how chronic headache affects daily life. The study took place in Norway. Norwegians receive conventional medical treatment either highly subsidized, or free of charge, within the public health care system.

Recruitment

The sample was taken from patients referred from the pain clinic and neurological department at a Hospital Trust and from General Practitioners (GP) in the south of Norway. Patients not referred by a neurologist received a full clinical examination and an MRI scan of the head and neck. Baseline recordings regarding headache frequency were examined to confirm the diagnosis.

Inclusion

18 to 70 years of age

Recent neurological examination and MRI scan of the brain and cervical spine (no longer than 6 months prior to inclusion).

Diagnosis of primary headache

Diagnosis of a chronic headache defined by *the International Headache Society 2nd Edition* [HIS].⁴

Medication initiated more than 3 months before inclusion could be

continued.

Exclusion criteria

New treatments for headache, including drugs initiated within 12 weeks prior to inclusion.

Severe psychiatric conditions.

Severe systemic disease.

Pregnancy.

Current use of opioids.

Drug/alcohol abuse.

Inadequate Norwegian language skills.

Before completing the interviews, participants were informed about the aim and purpose of the study, and about security measures concerning interview content and publication information. Written informed consent was obtained from each individual before conducting and recording the interviews. The study participants were informed that they could withdraw from the study for any reason and at any time, without consequences for future medical treatment. A sample of 16 was considered sufficient to achieve saturation.²⁰

Participants

Sixteen patients with chronic headaches were included. (Table 1: demographic data of the participants). They were recruited from a pain clinic at a Hospital Trust in the south of Norway, where interviews took place. The clinic is organized under the department of anaesthesiology. The multidisciplinary team includes medical consultants, a psychologist, a physiotherapist/acupuncturist, cognitive therapists and anaesthesia nurses. Interdisciplinary examinations of patients suffering from chronic pain syndromes aim to identify the type(s) and cause(s) of pain, and the level of functional disability, in order to tackle the complex issue of pain management.

Data collection

Interviews were semi-structured, an interview guide developed by the investigators based on a review of the existing literature (see supplementary material) was used. The interview guide was not tested before use. The second author (EBF), who is a cognitive therapist working at the clinic, conducted the interviews during the period 1 December 2019 to 30 April 2020. The interviews were tape-recorded and took place at the clinic during working hours. Most of the interviews took 45 min to complete. Interviews ranged in length from 30 min to one hour.

Data analysis

Each interview was transcribed verbatim and translated into English as soon as possible. The first (JH) and last author (TS) read all transcripts multiple times. They individually synthesized information from different parts of the transcripts and wrote case summaries.¹⁹ Topics based on questions from the interview guide and other information received were discussed. Categorized collective information for all 16 case studies was further analysed to create a variable-based analysis, where the variables were organized into components of five main domains (*emotions related to headaches; trauma/stressful events; behavioural changes; relationships and coping mechanisms*) (table 2). The analysts then returned to the interview text in an iterative fashion to search for more details, commonalities and contrasts. One of the domains (emotions related to headaches) was developed before the analytic process, and the others ($n = 4$) were developed during the analytic process. The transcripts were not returned to the participants for comments.

Methodological considerations

To evaluate the trustworthiness of this qualitative study, aspects of

Table 1
Demographic data of the participants.

ID	Age	Marital status	Highest level of education	Children	Work status
(ID9)	60	Divorced	Lower-level university/college	One adult child lives full-time with the mother	100%
(ID12)	59	Married	Lower-level university/college	Two adult children	25%
(ID8)	44	Cohabitant	Upper secondary education	Four children part-time (2 own, 2 are partners)	0%
(ID13)	68	Married	Lower-level university/college	2 adult children	0%
(ID11)	45	Married	Vocational education	Two children	100%
(ID 1)	44	Married	Higher-level university	Three children	Sick leave for the last three months (100%)
(ID2)	43	Divorced/single	Lower-level university/college	Two children (part-time)	40% work; 60% work assessment allowance
(ID10)	50	Married	Lower-level university/college	Two children	40% work; 60% work assessment allowance
(ID5)	53	Divorced/single	Lower-level university/college	Two adult children	Sick leave the last nine months (100%)
(ID3)	45	Divorced/single	Upper secondary education	One child	0%
(ID6)	38	Cohabitant	Lower-level university/college	One child	20% work; 80% work assessment allowance
(ID7)	39	Cohabitant	Lower-level university/college	One child	Maternity leave Previously 40% work; 60% sick leave
(ID4)	49	Married	Upper secondary education	Two children	40% work; 60% work assessment allowance
(ID15)	61	Married	Lower secondary education	Two adult children	20% work; 30% sick leave; 50% disability pension
(ID16)	62	Married	Upper secondary education	Three adult children	40% work; 60% work assessment allowance
(ID14)	59	Divorced	Lower-level university/college	Three adult children	100%

Table 2
Domains and subdomains in this study.

Main domains	Subdomains
1. Emotion related to headaches	a) Shame b) Anger c) Sadness
2. Trauma/stressful events 3. Behavioural changes	a) Loss of identity b) Playing a role c) Lack of freedom
4. Relationships 5. Coping strategies	

credibility, dependability, and transferability, were addressed by the researchers. A total of 16 patients agreed to take part in face-to-face interviews. More than 16 interviews may have resulted in a richer variety of experiences. However, no further substantial variation was added during the final three interviews. We concluded that the information power was sufficient and that a larger number of interviews would not have significantly altered the outcome of the thematic analysis.²²

Describing the research context and the participants' demographics allows readers to consider the relevance of formulated domains and the transferability of the findings. Credibility was established by presenting examples of the stepwise analysis process and interview excerpts.¹⁹ The first (JH) and the last (TS) author were responsible for the analysis process; all authors agreed on the interpretation of the results. This collaboration in the research team ensured dependability of the findings. Furthermore, this paper was written according to the criteria for reporting qualitative research.¹⁹

Results

The following five domains were identified: *emotions related to headaches; trauma/stressful events; behavioural changes; relationships and coping mechanisms.*

Description of the sample

Twelve women and four men were included in this study. The mean age of the participants was 51.2 years (range 38–68). One participant had completed basic education (primary school), four had completed secondary school and eleven had completed higher education. Only three participants worked full-time, the majority ($n = 7$) worked part-time and three of the participants could not work at all. The reduction in capacity to work was due to headache symptoms in all 10 cases, they all received some degree of disability allowance. Two participants were retired, and one was on maternity leave.

Emotions related to headache

Emotions affect motivation and drive. Emotions often arise when needs are either not satisfied or are hindered. Cognitive conditions influence emotions; a person's interpretation of a situation determines which specific emotion is triggered. As such, emotions can act as a driving force for behaviour.²³ When participants were asked about feelings related to their headaches, a total of 14 (ID1, ID2, ID3, ID4, ID5, ID6, ID8, ID9, ID10, ID11, ID12, ID13, ID 15, ID16) described their headaches as a complicated experience directly related to emotions. The majority of the participants ($n = 9$) said that *anger, shame, and sadness* (ID1, ID2, ID4, ID5, ID6, ID9, ID10, ID12, ID13) were dominant emotions that arose when they thought about their headaches.

a) Anger

Anja (ID4) signed up for a headache support group that did not help her. Talking about her headache just made it a bigger part of her life: *I get so pissed off, so angry, even at little things that don't mean anything, angry all the time! I have such a short fuse. The aching spreads to the whole of my head and then there are the daily migraines. Never a day without pain. I am never relaxed.*

Bente (ID10), a wife and mother said: *Im often angry and I swear a lot, I didn't used to. Everything annoys me. Little things that don't mean anything. I become easily overwhelmed, sometimes I cry, not because Im sad but because Im angry. Even in front of my kids, I can explode.*

Kari (ID9) woke up with a headache every day. *I manage daily routines quite well, even in my job as a childminder. I just feel constantly frustrated and irritated, it is never-ending.*

a) Shame

Shame is an unpleasant self-conscious emotion, associated with negative self-evaluation and the withdrawal of motivation. Typically, it involves feelings of distress, exposure, mistrust, powerlessness and worthlessness.²⁴ Shame often arises when an individual's actions conflict with their principles and expectations, or those of society. A situation that often jeopardizes social bonds. Eight participants (ID1, ID 4, ID7, ID8, ID10, ID 12, ID13) mentioned shame when talking about their headaches.

Rose (ID7) felt that she was never good enough. *As a child, mum belittled me and put me down and I let her. Inexplicable shame has become part of me. If I had been stronger, my headache might never have started.*

Bente (ID10) felt ashamed because she often let friends down by cancelling appointments. *I get fed up of explaining, It is embarrassing making excuses. Its horrible never being able to make plans with friends and family, it is impossible to predict how I will feel.*

Mona (ID12) always felt shameful when buying medicines: *I feel judged, I feel like they look down on me. I am embarrassed, I don't know why, it's like I am an addict! I go to different pharmacies so that I don't meet the same shop assistants.*

a) Sadness

Seven patients related sadness and loneliness to their headaches (ID2, ID4, ID6, ID 8, ID9, ID15, ID16).

Gro (ID2), a woman in her early forties, was resigned to not getting better. *I feel sad- numb, completely numb, like a zombie. I don't think about getting better, I just try to make it through the next hour.*

Mari (ID16) usually got a headache after lunch, as a consequence she had to get through all her daily tasks in the mornings. *I suppress bad emotions connected to my headache. I can't allow them to emerge because the pain worsens, making me sad, depressed, and knocked out for several days. Ive been through this so many times, so now I try to stop them [the emotions, author comment] as best I can.*

Mona (ID8) often cried when driving and at night. She elaborated: *I carry a feeling of loss around, as if part of me has died. It makes me tired, sad, and lonely.*

When the male participants (ID3, ID11, ID12, ID15) were asked about their emotions, their responses were more restrained and unclear, compared to the women.

Fredrik (ID3) said: *I don't know. Confused? Resignation? Fatigue? It affects my feelings. Sometimes I do not have the energy to feel anything.*

Arne (ID15) a retired sailor, thought that his headache was due to heavy smoking. *Emotions- I don't know what I feel when I think about my headache. Exasperation perhaps.*

In summary: The participants expressed a range of feelings when thinking about their headaches. Women expressed these emotions more freely than men. Research has shown that women are usually more emotionally expressive, at least in Western cultures.²⁵ Men often show equal or greater levels of physiological arousal associated with feelings, compared to women. These physiological changes include an increase in blood pressure and cortisol levels, measured in response to emotionally arousing stressors.²⁶ This internal arousal may be a response to keeping their emotions in check.

Trauma/stressful events

In psychology, the term trauma is used in situations that adversely affect the individual's mental health or personality development.²⁷ Ten participants (ID1, ID3, ID4, ID5, ID7, ID11, ID12, ID13, ID14, ID16) believed that trauma was the reason for their headaches. Four of these (ID1, ID11, ID12, ID16) started getting a headache after a physical trauma such as concussion, surgery, car crashes, and sports injuries, the rest related their headache to psychological trauma.

Katrine (ID1) had suffered from a headache for more than 15 years

after a concussion. *It is so draining and tiring, I need quiet. I don't have the energy to discipline the children, stand up to my husband, or even keep up with chores. I feel like a failure.*

Two car crashes resulted in head pain for Jens (ID2), who has not worked for the last eight years. *Injections into the nerves in my neck stopped being effective after 4 years. Now my head feels tense and foggy.*

Six participants (ID3, ID4, ID5, ID7, ID13, ID14), referred to psychologically traumatic events when talking about their headaches.

Une (ID13) related her symptoms to an event from nearly 20 years ago when her husband left her for another woman. *I was healthy and happy, but out of the blue, my husband came home from work saying he had fallen in love with another woman. He left me the next day. My head and body started aching and I lost all my confidence. I thought that it was a shock, but 10 years later the symptoms have not gone away.*

Jessica (ID5) experienced a similar episode. *The moment I found out that my husband was having an affair, my shoulders and back started aching, I got tired from doing nothing and my forehead felt like it might explode. The pain is still there.*

Rose (ID7) connected her headache to an unhappy childhood. She felt guilty for not standing up to her mother. *My childhood was unstable. I was always anxious when my brother and I were left alone in the evenings, sometimes all night. My parents didn't provide a safe, predictable home life. I don't think that they ever really loved us.*

In Summary: Exposure to stressful events may initiate illness, influencing affect, behaviour and physiology. Evidence suggests that a relationship exists between stressor exposure and a selection of common illnesses responsible for a large proportion of morbidities and disabilities.²⁸ The majority of the participants in this study related stressful situations to the onset of their symptoms.

Behavioural changes

a) Loss of Identity

Many of the participants (ID 1, ID3, ID6, ID8, ID10, ID16) ($n = 6$) felt that chronic pain had negatively affected their personalities. Turning them into someone they neither liked nor wanted to be. Participants talked about grieving for their former selves.

Nelly (ID6) explained: *I have become another version of myself. I am sick of living carefully. Social media tells me that my peers are travelling, eating out, drinking, and earning a load of money. It gets me down*

Katrine (ID1) agreed: *I have become another version of myself. I have become somewhat egocentric; I don't want to be like that. I feel like I have become distant like I am looking at myself from afar. My response patterns have changed.*

Mona (ID8) felt like a washed-out, weaker, duller version of herself. *I lost myself, somewhere. My identity – gone, washed away by pain and illness. I don't know how to find myself again.*

a) Playing a role

Seven patients (ID 2, ID4, ID7, ID8, ID10, ID11, ID 12, ID 13) described role-playing. Playing a healthier, more functional version of themselves in order to hide the reality of their situations from society and in some cases their families.

Bente (ID10) explained that she constantly put on an act with the kids, pretending that she was healthy. *I do not want them to think that growing up with someone who is ill, is normal. So, I put on an act. I am quite good actually, but it takes its toll.*

Heidi (ID14) described the need to always look attractive and presentable, to appear healthy. *I get my highlights and nails done regularly. I never leave the house without applying full makeup, and I spend ages deciding what clothes to wear. It is important to me. If I look good, I avoid pity. When things are bad, I hide away at home, I don't even answer the door.*

a) Lack of freedom

In the 1970's George Vithoulkas, a Greek author and practitioner of homoeopathy postulated that lack of freedom is a consequence of bad health.²⁹ Five participants (ID 2, 4, 6, 7, 16) described this phenomenon when talking about their complaints.

Anja (ID4) spent a brief period in prison as a result of drunk driving, the experience was followed by years of shame. *I am telling you this because having a headache is like a prison sentence. It limits everything in everyday life. It limits me in all my roles as a mother, wife, cook, friend, and sexual. The pains put a stop to ambitions and goals. I'm not free.*

Rose (ID7) also had to plan. *Just going out for a walk means that I need to schedule time for a rest afterwards. More than a couple of tasks a day leaves me with a pounding headache.*

Marit (ID16), has had a headache for the last six years. *I miss having freedom in my life. Everything needs to be kept under control – to be predictable.*

In summary: The subdomains: *loss of identity, lack of freedom, and reluctant adaptation to a new role* were strongly connected. Pain and the consequence of functional disability deprived the participants of the opportunity to live normal lives. With that followed a drop in social status, self-esteem, and physical well-being, which was perceived as shameful. Not being able to live their lives as they used to, was connected to the loss of identity. Coping meant having to adapt to living a restricted and isolated life, with few activities. This was perceived as a lack of freedom.

Relationships

Family bonding is the time families spend together interacting and supporting each other. Social support acts as a buffer for the negative effects of stressful events. Research shows that people with high levels of emotional support have an overall lower risk of mortality.^{30, 31} Participants said that relationships with friends and family had been affected by chronic pain. Seven participants (ID 2, 3, 4, 6, 7, 15, 16) said that they spent more time with their families, but less time with friends and colleagues after their headaches started.

Nelly (ID6) said: *I am closer to my family now but have distanced myself from friends. I am more emotionally open with the family. I can tell them that I am having a bad day without feeling judged.*

Fredrik (ID3), a former businessman and divorcee looked after his daughter part-time. *I want to make sure my daughter has a good life. That is why I worked so hard before. Now I am on disability pay, it's nothing compared to what I previously earned. I worry a lot about financial security, especially for my daughter.*

Marit (ID16), talked about change and acceptance, about becoming introverted, a stark contrast to the extreme extrovert she used to be. *My family thinks it is OK that I've changed. They seem to respect my way of doing things now and they help me more often. I used to help them all, and organize them all the time, even though my husband and children never appreciated it. Now we work together. They are learning to be independent instead of relying on me.*

Although participants reported spending more time at home with close relatives, intimate relationships appear to have suffered in some cases. Five participants (ID 1, 4, 8, 10, 12) mentioned that their headaches negatively affected their sex lives.

Jens (ID12) explained: *We don't have sex anymore, I can't. The pressure builds up in my head.*

Mona (ID8) confided: *We are no longer intimate and therefore not as close as we used to be.*

Bente (ID10), and her husband found a compromise. *We sleep in separate rooms when I have bad days. It works for us, after all, we've been together for 22 years. We've agreed to have sex at least once a week, on my "good days." Planning sex is not ideal, but it helps us maintain a certain degree of intimacy.*

By contrast, Arne (ID 15), was not close to his partner. During many years as a sailor alcohol, smoking, and irresponsible sex had already taken its' toll on family life. *I have big regrets – mostly because of the family. The bad habits didn't stop when I stopped sailing and started working on shore. We haven't been close for years.*

In Summary: Headaches and lack of energy resulted in many participants staying at home more than they used to. Family bonds appeared to have been strengthened, intimate relationships appear to have suffered and friendships were often lost or weakened.

Coping strategies

A coping strategy is an action, a series of actions, or a thought process used in stressful or unpleasant situations, or in modifying a reaction to such a situation. Coping strategies typically involve a conscious and direct approach to problems.³⁰ Six participants (ID 1, 3, 6, 8, 10, 16) found tools to cope with their chronic pain situations.

Rose (ID7), pretended to have had a fulfilling day when the family asked her what she had been doing. She said: *I am ashamed of being useless, so I pretend, to protect them and retain some degree of dignity – even though it is false.*

Ella (ID14), a 59-year-old woman, often experienced negative emotions and feelings of worthlessness. After a humiliating episode that significantly increased her headache, she uncharacteristically had a facelift. *The strange thing is that I wasn't worried or afraid. Afterward I was really high! I didn't need painkillers and my headache was completely gone for about a week. How can I regain that positive feeling that erased my headache? I wonder whether antidepressants might have the same effect, I don't dare to discuss it with my GP. A psychologist, maybe?*

Jens (ID12) found regular acupuncture helpful. *It helps but I still can't concentrate enough to use a computer, but now reading is no problem, - it's a big improvement.*

Mari (ID16) found a way of distracting herself from negative emotions and pain. *I bake bread. I didn't use to enjoy baking, but now I love finding different recipes, the smell, and all the practical things - kneading, stirring, measuring, and eating. Baking stops me from thinking too much. The radio and the smell of baking calm my soul.*

Discussion

This study aims to explore the lives and experiences of headache sufferers. Sixteen participants reported a life with a lot of pain resulting in disability. Headaches prevented many of the participants ($n = 10$) from being able to work full-time. Ten people believed that trauma was the reason for their headaches; they expressed anger, frustration, and irritability when thinking about their headaches. Shame and a loss of identity were topics frequently discussed and strongly identified as a consequence of chronic illness. Lack of freedom and flexibility was a frequent complaint, planned activities often had to be cancelled when symptoms increased. Activities had to be arranged around headaches. Almost half of the participants ($n = 7$) reported that keeping contact with friends was difficult, family relationships mostly became closer, but intimate relationships often suffered.

Other studies

Although headaches were reported as draining, some participants ($n = 6$) found ways to cope that included medical treatments, hobbies, or other focus points. However, in general participants' lives were restricted. The impact of reducing stress is unknown. However, stress management and relaxation techniques are validated treatments for migraines and may also be helpful for chronic headache patients, who frequently experience stress, or cope with it poorly.¹² Focus on the good things in life to reduce stress is a finding reported by two studies conducted in Sweden.^{16,17} Findings common to our study were reported in a systematic review of qualitative literature titled *the lived experience of*

chronic headaches.¹⁸ Four studies were included, and 52 of the 73 participants were female, the gender proportion was similar to our study. Results indicated that headaches affected behaviour, restricting daily life, and leading to a feeling of loss of control. When the headache acts as a driver of behaviour, it also affects relationships. In our study, it often led to less time spent with friends, which combined with not being able to work created feelings of worthlessness and isolation, a finding also described in a study by Jonsson et al.³¹ Many of the issues raised in our study such as impaired quality of life, relationship issues, uncertainty and the emotional impact of the condition, resonate with a multitude of other chronic pain conditions, such as low back pain³² and fibromyalgia.³³ Chronic conditions that are not backed up by biological indicators, blood tests, or scans are often devalued by society,³⁴ denying sufferers objective measurements to support their conditions.³⁵ Disease prestige in medical culture was examined in three surveys carried out over a 25-year span. Norwegian physicians rated medical conditions that demand invasive actions and complicated technologies higher than chronic diseases. Conditions classed as primary pain diseases such as fibromyalgia and idiopathic headaches were ranked lowest. Female-dominated conditions were ranked lower than comparable conditions typical for men. Results showed remarkable stability in prestige ranking when the survey was repeated after 12 and 25 years.³⁶ Leading to the assumption that less prestigious conditions, approached with less motivation, can potentially delay correct diagnosis and treatments. Stigma is often associated with lower-ranked diseases, affecting patients' expectations in clinical situations, and creating feelings of being judged and rejected. Coping with societal insults (real or imagined) can endanger personal identity, social life, and economic opportunities. Information received in our study revealed factors of female dominance, low disease prestige and stigmatisation. Multiple low-status factors can easily lead to a cumulative situation of suffering and hopelessness, which is hard to change.

Theory of life course approach and embodiment

Ten participants believed that trauma was the reason for their symptoms. Four participants reported headaches after physical trauma and six referred to psychological events. Similar findings have been reported previously in both migraine and headache sufferers.^{7, 12, 13} Stressful events have been associated with an increase in disease risk.¹ Contribution to the onset and maintenance of pain syndromes by affective dysregulation can manifest itself in anxiety, fear, and depression. In some cases biological and/or behavioural stress factors such as drinking, eating disorders, and smoking compound stress situations.³¹ Definitions of what constitutes a stressful event vary, such events are generally considered to be major occurrences such as death of a spouse, sexual assault, or being diagnosed with a serious or terminal illness.³¹ Such events will often result in psychological and physiological stress responses for the average person. Rarely are common everyday events we have encountered in this study, such as infidelity, divorce, humiliation, accidents, and unmet emotional needs considered warning signs, where the loss of health is concerned. These findings correlate with the *life course approach* and the theory of *embodiment* discussed earlier, describing how extrinsic and biological factors offer a complex understanding of chronic diseases.¹⁴

Most research considering stressful events and trauma focus on episodes from childhood. There is little evidence regarding adult trauma. Ethical considerations prohibit conducting experimental studies in humans regarding the effects of enduring stressful events.

Strengths and limitations

This study should be interpreted considering its strengths and limitations. Qualitative analysis provides insights into how participants understand and interpret situations, but it cannot be used to establish associations.³⁷ Sixteen participants agreed to be interviewed. Having

more than 16 interviews may have resulted in an extended variety of experiences. However, no further substantial variation was added during the final three interviews, leading to the conclusion that the information power was sufficient, and that a larger number of interviews would not have significantly altered the outcome of the thematic analysis.²⁰ Moreover, the in-depth interviews provided rich, complex material and the participants demonstrated striking similarities in their personal histories, concerns, and strategies. This study was based on data from a selected group of participants recruited via Vestfold Hospital Trust. The present findings may not be representative for headache sufferers from other areas in Norway.

Implications for clinical practice and further research

Chronic headache is a complex disease. More research is needed regarding the identification of risk factors, in order to provide early intervention and reduce the likelihood of chronic symptoms. Evidence from this study indicated that chronic headache is a complex condition with many far-reaching adverse effects. The implementation of individually tailored treatment approaches may have the potential to improve physical and psychological function. Holistic patient education should include themes such as cultural and social rights, alongside typical information on pain physiology and management, sleep hygiene, exercise, and nutrition.

Traumatic events can act as a trigger for chronic conditions, these factors need to be identified and monitored by clinicians, as do ongoing events that maintain or exacerbate symptoms. Research has shown that women are more prone to primary pain syndromes. Clinicians, especially general practitioners need to be diligent regarding this gender ratio, in order to identify potential risks in an early phase.

Only three of the 16 participants in this study were men. Information given during interviews by the men was more pragmatic and restricted than the information given by the women. It is possible that clinical approaches need to be adjusted according to gender. Also, other methods of collecting qualitative information, such as anonymously written statements may be more appropriate to gain broader and richer information from men.

Conclusion

This study provided an in-depth understanding of how chronic headache adversely affects the lives of sufferers. Chronic headache restricts sufferers' lives, resulting in emotional and behavioural changes. The majority of the participants thought that traumatic events had initiated and to some degree maintained their symptoms. Most of the participants were frustrated over the public's general lack of knowledge and understanding of how disabling and restricting headache is. Clinicians need to be more aware of the complexity of chronic headaches to identify risk factors and provide individually tailored support systems and treatment approaches.

Authors' contributions

JH developed and designed this study. EBF conducted the interviews. TS and JH analysed the data and drafted the manuscript. All authors have read and approved the last version of the manuscript.

Availability of data and materials

Security and confidentiality concerns prevent datasets generated and/or analysed during the current study being publicly available. Anonymously labelled data is available on request.

Ethics approval and consent to participate

Written informed consent was obtained from all participants before

being interviewed. All the participants were informed that they could withdraw from the study without giving a reason. The study was approved by the Norwegian Centre for Research Data (NSD), reference code: 754,483. This study meets the standard of the Helsinki Declaration of 1975 last revised in 2013 (39).

Consent for publication

Consent to publish was obtained from the participants.

Acknowledgements

We would like to express our gratitude to the patients who participated in this study. Publication charges for this article have been funded by UiT, The Arctic University of Norway.

Funding

This research has not received any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.explore.2023.01.004](https://doi.org/10.1016/j.explore.2023.01.004).

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