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Recognizing, Accepting, and Belonging: Patient Learning and Experiences in a Structured Headache Education Program

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Background and Aim: Chronic headache disorders substantially impair quality of life, daily functioning, and social participation. Acceptance and Commitment Therapy (ACT), a third-wave cognitive-behavioral approach, has shown promise in chronic pain management, but little is known about patients' lived experiences with ACT-based group treatment. This study explored how individuals with chronic headache experienced participation in The Headache School, a multidisciplinary ACT-informed program delivered at a specialized Danish headache clinic, with focus on knowledge gains, daily life changes, and the impact of the group setting.

Methods: A qualitative design was applied using focus group interviews. Participants were purposively sampled among patients who had completed at least nine of eleven sessions of The Headache School between 2019 and 2024. Data from nine focus groups with 36 participants were analyzed using reflexive thematic analysis following Braun and Clarke.

Results: Three overarching themes were identified: (1) *Knowledge and recognition that it is a real illness*, (2) *Accepting that the illness will always be part of my life*, and (3) *Belonging – I did not have to explain, apologize or defend myself*. Patients described increased self-understanding, greater acceptance of their condition, and improved ability to communicate needs and limitations. The programme supported value-based life choices and prioritization of well-being despite ongoing symptoms. The group format fostered community, reduced isolation, and offered long-term peer support.

Conclusion: Participation in The Headache School was experienced as meaningful and supportive, facilitating acceptance, psychological flexibility, and empowerment. Patients reported enhanced capacity to live functional, value-driven lives despite persistent headache. The group format played a central role in reducing isolation and fostering lasting connections. These findings highlight the potential of ACT-informed, multidisciplinary group interventions in chronic headache care and emphasize the importance of incorporating patient perspectives into treatment development and evaluation.

Trial Registration: Registered with the Region of Southern Denmark (24/32787).

Keywords: chronic headache, group treatment, acceptance and commitment therapy, qualitative methodology, focus groups, biopsychosocial model

Introduction

Chronic headache disorders affect approximately 1–4% of individuals suffering from headache, defined by the occurrence of 15 or more headache days per month for a minimum of three consecutive months.[1] In specialized headache clinics, around 40% of patients are diagnosed with a chronic headache disorder.[1] Chronic headache encompasses various subtypes, including chronic migraine and chronic tension-type headache.[1] Characterized by their persistent and disabling nature, chronic headache disorders significantly impair quality of life, often leading to social withdrawal and reduced occupational functioning.[2–4] Increasing recognition of patients lived experiences further highlights the profound negative impact of these conditions on daily life.[5–7]

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In general neurological practice, the treatment of headache is typically guided by a biomedical model, which conceptualizes pain as a physiological dysfunction amenable to pharmacological interventions.[8] In contrast, specialized headache clinics increasingly adopt a biopsychosocial framework, recognizing that headache is shaped by a complex interplay of biological, psychological, and social factors.[9,10] This multidimensional perspective challenges the biomedical model's assumption of monocausality and acknowledges the influence of societal norms, healthcare structures, and values on the definition and recognition of disease.[11]

The biopsychosocial model is well-suited for understanding and treating persistent pain, including headache.[12,13] Empirical support from theories such as the Gate Control Theory of pain underscores the multidimensional nature of pain and strengthens the rationale for a biopsychosocial approach in clinical practice.[14] Effective management of chronic headache thus necessitates interdisciplinary collaboration to address its complex and multifaceted nature.[15]

Psychological interventions informed by the biopsychosocial model, especially Cognitive Behavioral Therapies (CBT), have demonstrated efficacy in chronic pain management.[16] However, traditional CBT largely aims to modify maladaptive cognitions to reduce symptoms, whereas Acceptance and Commitment Therapy (ACT) represent a third-wave development emphasizing psychological flexibility rather than symptom elimination.[17–19] ACT differs from CBT by focusing less on changing thoughts and more on changing the individual's relationship to thoughts, emotions, and physical sensations.[20] Grounded in functional contextualism and Relational Frame Theory, ACT targets experiential avoidance and promotes acceptance, values clarification, and committed action.[20,21] Through processes such as acceptance, cognitive defusion, mindfulness, self-as-context, values-based behavior, and committed action, ACT helps individuals pursue meaningful activities despite persistent symptoms.

Mindfulness, a core ACT process, has been shown to enhance pain tolerance, reduce emotional reactivity, and increase self-efficacy, supporting patients in functioning despite pain and improving quality of life.[20] In chronic pain populations, including those with chronic headache, ACT has demonstrated improvements in pain-related disability, quality of life, and daily functioning.[22–24]

Group-based ACT formats may further enhance outcomes by providing peer validation, normalization, and shared learning, strengthening acceptance and adherence.[25] However, despite promising evidence, little is known about how patients themselves experience ACT-based group education for chronic headache and how learning processes translate into everyday life.

The Headache School is a multidisciplinary, ACT-based group treatment program delivered in a specialized headache clinic at a university hospital in Southern Denmark. This qualitative study addresses a key research gap by exploring patient experiences with this ACT-informed program, with particular attention to how ACT principles support living meaningfully with chronic headache. Specifically, the objectives were:

- To explore whether the knowledge patients reported gaining from The Headache School supported them in living a meaningful and functional life despite chronic headache.
- To examine the perceived changes in patients' daily lives following participation in The Headache School.
- To explore patients' experiences of engaging in a group-based setting alongside others living with chronic headache.

Methods

Study Design

A focus group methodology was employed to facilitate discussions among patients, enabling the collection of nuanced data grounded in their experiences with participation in The Headache School.[26] The focus group interaction proved beneficial, as listening to others share their experiences encouraged patients to reflect on and recognize the significance of their own experiences. This environment facilitated the exploration of both commonalities and differences among patients' perspectives.[27] The method was particularly well-suited for replicating the social dynamics characteristic of group-based interventions such as The Headache School.[28,29] Data were analyzed using reflexive thematic analysis as

outlined by Braun and Clarke.[30,31] Patients how had attended the headache school between 2019 and 2024 participated. A total of nine focus group interviews were conducted with 1–6 participants per group.

As this is a qualitative study grounded in an interpretivist paradigm it sought to develop an in-depth understanding of patients' lived experiences and meaning-making processes. Accordingly, rigor was ensured through analytical depth, transparency, and reflexive engagement. To ensure adequate data for thematic development, we followed a principle of information power. Focus groups continued until data provided rich experiential accounts that supported the emergence and refinement of coherent themes aligned with the study aims. Theme development therefore reflected analytical depth and interpretive completeness rather than numerical saturation.[30,32]

The Headache School

Established in 2017, The Headache School was grounded in the biopsychosocial model and ACT.[11,20] ACT, promotes psychological flexibility, the capacity to experience pain while acting in accordance with personal values, through six core processes: present-moment awareness, acceptance, cognitive defusion, self-as-context, values, and committed action.[20,33] Furthermore, metaphors constitute a central pedagogical component in ACT, and during The Headache School metaphors such as the "Spoon Theory" were actively applied to help patients illustrate and communicate energy limitations, pacing, and value-based prioritization in daily life, thereby translating abstract psychological principles into tangible lived strategies.[21] The Headache School was designed to equip patients with knowledge, personal insights, and behavioral strategies aimed at promoting a well-functioning and meaningful life despite the challenges of living with chronic headache.

Aligned with a multidisciplinary approach and the biopsychosocial model, psychological treatment served as The Headache School's foundation, combined with nurse-led education and physiotherapy-supervised training. Physiotherapy focused on improving body awareness, balancing activity with relaxation, and addressing bodily tension. Chronic headache patients often struggle with imbalanced activity levels, either too low or too high.[34] The physiotherapy training program followed the Danish Health Authority guidelines for non-pharmacological migraine and tension headache treatment.[35] It included graded cardiovascular exercise, strength training, and relaxation techniques. The training was tailored to patients' daily lives and interests to enhance motivation while encouraging progress without overexertion. Table 1 outlies the content of each session, including the ACT topics covered.

Table 1 Content of Each Session, Including the ACT Topics Covered

	Psychological Education (Psychologists/Nurses)	Core Processes (ACT)	Physiotherapy-Supervised Training (Physiotherapists)
1	Introduction to the Headache clinic and why this group of patients are referred to The Headache School (due to the chronicity of the headache) Education by nurses. Participation by the psychologist	Education regarding chronic headaches as an illness. Meaning using a multidisciplinary approach based on the biopsychosocial model *Self-as-context and acceptance*	Introduction to the psychological intervention plan in accordance with the biopsychosocial model Education by physiotherapists. Participation by the psychologist
2	Pain theory including the biopsychosocial model as a foundation for the program	Psychoeducation and meaning as a motivational factor (compliance to the intervention)	Graduated training including relaxation
3	ACT as a pain treatment, previous medication, and alternatives treatments	*Self-as-context and acceptance*	Graduated training including relaxation
4	Pain and suffering	*Self-as-context and acceptance*	Graduated training including relaxation
5	Values	*Values*	Training including rubber bands
6	Negative automated thoughts	*Cognitive defusion*	Graduated training including relaxation
7	Present moment	*Contact with the present moment, cognitive defusion and acceptance*	Mindfulness
8	Acceptance	*Acceptance*	Stain training

(*Continued*)

Table 1 (Continued).

	Psychological Education (Psychologists/Nurses)	Core Processes (ACT)	Physiotherapy-Supervised Training (Physiotherapists)
9	Committed action based on values	*Committed action and values*	Slow pace walking in a forest
10	Committed action and barriers to success	*Committed action*	Graduated training including relaxation
11	Follow-up attendance of both patients and their close relations	*Consolidation of all six core processes – physiological flexibility*	Graduated training including relaxation

The Headache School took place at the hospital in groups of 8–10 patients across 11 weekly sessions, followed by an additional session two months after completion, to which patients' close relations were invited. Each session comprised two hours of structured psychoeducation delivered by a psychologist, supported by a nurse, followed by a 30-minute break. This was succeeded by one hour of guided physiotherapy led by specialized physiotherapists. All involved healthcare professionals were highly trained and experienced in the management of chronic headache conditions.

Participants and Setting

The study was specifically designed to explore patients' lived experiences of participating in the full ACT-based program. To ensure meaningful reflections on the program's processes and outcomes, only those who had engaged sufficiently were considered eligible. A purposive sampling strategy was therefore applied, targeting patients who had attended The Headache School and could provide informed perspectives.[27] All individuals who had completed at least nine of the eleven sessions between 2019 and 2024 were invited to participate and asked to contact the researchers if interested. Patients represented a wide range of backgrounds (education, family structure), They also varied in their headache profiles, including type, intensity, frequency, duration, and trigger factors. This diversity was intended to enhance data richness while reflecting the heterogeneity encountered in clinical practice. Patients were referred to The Headache School following a multidisciplinary clinical assessment. This assessment included consultations with a neurologist for diagnostic evaluation, a headache nurse specialist, a physiotherapist, and a psychologist, after which patients were jointly evaluated in interdisciplinary team meetings to determine their eligibility for the program. Communication difficulties and psychosocial burden were identified through clinical interview with the psychologist, documented patient history and medical records. Inclusion criteria were:

- Diagnosed with a chronic headache by The International Classification of Headache Disorders (ICHD-3) criteria[1] and had suffered from a chronic headache > 2 years
- Previously treated with pharmacological therapies without sufficient relief (reduction in amount of headache days pr. month and/or reduction in pain intensity and duration)
- Experienced unacceptable side effects of the pharmacological treatment
- Self-reported functional limitations in daily function and activity
- Trouble communicating about an invisible disease in both close and distant relations
- Felt the above affecting their mental health negatively

Exclusion criteria included inability to speak or write Danish, cognitive impairments, and psychiatric disorders as the primary or predominant condition. Furthermore, patients suffering from medication overuse headache were excluded from participating.

Data Collection

Data were collected in June 2024. All focus group interviews were conducted at the hospital, audio-recorded, and lasted approximately 90 minutes. The interviews were facilitated by one of the authors (LSM), an experienced nurse and

researcher specializing in headache treatment, who had not previously attended The Headache School. Reflexive notes were kept before and after interviews to address assumptions related to ACT and headache care.

Patients were interviewed in the same groups they had attended during The Headache School to support familiarity and safety. Group sizes varied from one to six, depending on participants' availability. Prior to the interviews, the authors developed a semi-structured interview guide, organised into three primary areas reflecting the study aims: Psychological strategies and ACT tools, Management of headache in daily living, and Experiences of group-based participation. The questions were presented on discussion cards accompanied by illustrations familiar from The Headache School sessions. These cards were placed on the table to facilitate group discussions, with the illustrations serving as prompts for inspiration and reflection. An example of a question was: "Can you describe if and how the practical skills and strategies from The Headache School have impacted your life?"

Data Analysis

All interviews were transcribed verbatim.

The six phased process as proposed by Braun and Clarke was applied as an iterative and flexible approach to doing a reflexive thematic analysis.[30,36] In the first phase, the authors carefully read and re-read all the transcriptions to become familiar with the dataset. During this process, notes were made on interesting passages, and initial trends were identified. In the second phase, a systematic assessment of the data was conducted to identify and label passages potentially relevant to address the study aims. These passages were then generated as initial codes. This process resulted in development of 16 initial codes. During the third phase the authors focused on construing the relationship among the different codes across the dataset informing preliminary themes and subthemes. In the fourth phase all preliminary themes and subthemes were reviewed through an iterative process between themes and the original dataset. Based on this process some of the themes were revised as they did not reflect a meaningful interpretation of the data or did not inform the research aims.[37] In the fifth phase, the two authors engaged in collaborative discussions to refine, define, and name the final themes and subthemes. This process ensured alignment between the themes and the data's content while maintaining relevance to the research aims. Following this, the authors developed detailed and nuanced accounts of the findings, which are presented in the results and discussion sections below.[30,37,38] Representative quotations from the patients were selected for the results section illustrating the breadth and depth of each theme, prioritizing clarity, emotional nuance, and variation across participant experiences. Theme credibility was reinforced through the iterative analytic process, where both researchers reviewed quotations and coding patterns to ensure shared interpretive agreement.

Ethics

The study was conducted in accordance with the principles of the Declaration of Helsinki[39] and was registered with the Region of Southern Denmark (24/32787). As the study was non-biomedical in nature, formal approval from the Danish National Center for Ethics was not required for the use of interviews. This exemption is in line with the Danish Committee Act on Research Ethics Review of Health Research Projects (Consolidation Act No. 1083 of 15 September 2017, §14, subsection 2). Consequently, ethical approval was not sought. Authorization to conduct the study was, however, obtained from the management at the University Hospital of Southern Denmark, Esbjerg. Participation was voluntary, and patients received both oral and written information about the study. Written informed consent was obtained from all patients prior to inclusion. In addition, patients were informed that some of their statements would be used in anonymized form in a scientific publication. All data were anonymized and managed in compliance with the EU General Data Protection Regulation (GDPR), Regulation (EU) 2016/679. The study adhered to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist.[40]

Results

All 69 patients who successfully completed The Headache School were invited to participate. Of these, 47 patients (68%) agreed to be interviewed. Ultimately, 36 patients (52%) attended and completed the interviews, while the remaining 11 patients (16%) cancelled, primarily due to migraine attacks, other health conditions, municipal appointments, or urgent work-related obligations.

The patients were divided into the groups they originally participated in at The Headache School, resulting in nine focus groups interviews. Females were predominant (94%), and the mean age was 45 years. Working status was roughly divided equally into two overall categories "employed" and "unemployed." However, the Danish Social Welfare System holds an in-between attachment to the labor market (flex job) were people suffering from a chronic illness can work at a maximum of 17 hours/week while receiving payment as if they worked fulltime. A total of 21 patients had an attachment to the labor market (58%). The Table 2 shows an overview of demographic and headache characteristics of the included patients.

Three themes were constructed based on the reflexive thematic analysis to shed these experiences:1) *Knowledge and recognition that it is a real illness*, 2) *Accepting that the illness will always be a part of my life* and 3) *Belonging- I did not have to explain, apologize or defend myself*. The three themes are defined through seven subthemes, illustrated in Table 3.

Across themes, ACT-consistent processes such as values-based living, cognitive defusion, and perspective-taking were evident in-patient narratives, illustrating how psychological flexibility developed in a chronic headache context. Although

Table 2 Patients' Demographic and Headache Characteristics

	Participants (n=36)
Age, mean (range)	45.5 (30–67)
Sex n (%)	
Female	34 (94)
Male	2 (6)
Civil status n (%)	
In a relationship	32 (89)
Single	4 (11)
Working status n (%)	
Total employed (ordinary employment or flex job)	21 (58)
Unemployed/Sickness benefits/social welfare	15 (42)
Primary diagnosis n (%)	
Chronic migraine	10 (28)
Chronic migraine including tension type headache as a secondary diagnosis	13 (36)
Chronic tension type headache	5 (14)
Chronic cluster headache	2 (5)
Persistent headache attributed to traumatic injury to the head	4 (11)
Chronic trigeminal neuralgia	1 (3)
Headache attributed to idiopathic intracranial hypertension	1 (3)
Years lived with headache n (%)	
0-10	11 (31)
11-20	9 (25)
21-30	3 (8)
31-40	4 (11)
>41	9 (25)

Table 3 Themes with Subthemes

Theme	**Subthemes**
Knowledge and recognition that it is a real illness	• Energy Constraints and Setting Boundaries • Conscious Choices and Value-based Living
Accepting that the illness will always be a part of my life	• Acceptance and Openness About the headache • Reflective Communication of Thoughts, Emotions and Behaviour
Belonging-I did not have to explain, apologize, or defend myself	• Group Dynamics and Community • The Role of Community in Acceptance and Psychological Support • Supportive Friendships Beyond The Headache School

most patients described positive change, a small number expressed ongoing ambivalence toward acceptance or challenges in consistently applying strategies, which offered important contrast and further validated the thematic structure.

Knowledge and Recognition That It is a Real Illness

Energy Constraints and Setting Boundaries

The majority articulated the usability of recognizing energy constraints due to the chronic headache was central. Visual metaphors, such as the "Spoon Theory," were widely referenced as helpful tools in illustrating the need to balance activity and rest. These metaphors enabled patients to communicate that boundary-setting was not about avoidance but about preserving well-being. For patients living with chronic headache, such imagery also supported mutual understanding with close relations about the invisible demands of daily life. Several patients shared positive experiences of involving close relations in the Spoon Theory metaphor. One patient expressed: "The Spoon Theory has become a common language and understanding in our family". Another patient exemplified how her children would say: "So, Mom, don't you have any more spoons?" when she ran out of energy.

Recognizing the chronic nature of the headache prompted a shift in how patients approached everyday life. It encouraged them to reassess what was realistically manageable and supported meaningful changes in routines and priorities, enabling them to pursue a value-based life with the headache. Genuinely understanding their condition, patients began to take active responsibility for living with the headache, making conscious choices based on what mattered most to them within the constraints of limited energy exemplified by one of the patients: "You prioritize what matters most to you and what you have the energy for". Patients were compelled to prioritize core life values, acknowledging that they could no longer do everything they once could or wished to. This process also involved a painful, yet necessary, realization that the life they had known prior to the headache- the "healthy life" was no longer available to them. Expressed by a patient: "I find it difficult to live with, that you can no longer do what you once could."

Conscious Choices and Value-Based Living

Recognizing chronic headache as part of their life, without letting it define them, marked a profound shift. One patient said: "I think it's become easier for me to say that it's not all of me. Yes. The migraine isn't all of who I am". This acknowledgment enabled them to make deliberate, value-driven choices, rather than unconsciously striving to meet societal ideals and norms, which often involved unrealistic expectations. Several patients reported having spent years pursuing such unattainable standards, resulting in a lack of meaning and diminished quality of life. Exemplified:

> Well, society expects me to work full time for the rest of my life until I retire. And it is a process - something that has started a shift in my thinking now, this whole process of realizing that I simply will not do that.

This shift in mindset empowered patients not just to manage symptoms but to shape lives that remained meaningful despite headache. Rather than merely surviving with chronic headaches, they began learning how to live with it. One patient quoted: "You must live, not just survive. I think about that often," while another quoted

> Because it was pure survival. And right now. well, it was just, again, just pushing through, you know? Like, I can do this. Of course I can. I must. I just have to. Of course I can do it all. Without checking in with myself at all. So, this thing about it being allowed to feel-needing to feel, that's important

This theme expands existing ACT literature by demonstrating how illness validation and energy-management frameworks can enhance values-consistent action among patients with an invisible conditions.

Accepting That the Illness Will Always Be a Part of My Life

Acceptance and Openness About the Headache

Acceptance emerged as a complex, ongoing process requiring both emotional and practical adjustments. Patients expressed this in various ways: "It has a name," "I actually do have an illness," "the awareness of what it is.there's a reason why I feel the way I feel." Acceptance extended beyond a personal transformation as it also required a social shift patients learned to openly discuss their condition, its secondary symptoms, and the consequences often challenging

due to the instinct to conceal symptoms to appear “normal.” One patient said: “I’ve done everything I could to hide it”. The study revealed the struggle patients faced in balancing the pressure to present themselves as strong and capable while dealing with the internal limitations imposed by their headache.

Patients gradually learned to communicate about their headache, despite the difficulty of concealing symptoms to meet societal expectations of normalcy. This gradual process of openly expressing thoughts, emotions, and behaviors related to the headache was practiced verbally in The Headache School. Patients emphasized that this process was challenging and slow, yet essential, as it creates a positive feedback loop that enhances their own acceptance of the condition, as well as the acceptance from their close relations. One patient expressed it as: “I can better communicate what it actually feels like to be me and to live with my challenges”. When close relations understood the condition and acknowledged the associated losses in functioning, it became easier for patients to let go of the façade of being “normal” or healthy, and to stop fighting to maintain that image. In addition, it became easier for those around the patient to offer the appropriate help. One patient gave an example of how her husband, after reading The Spoon Theory, were able to help her in an appropriate manner: “Then he says, ‘Are you sure you have enough spoons for that?’ And that really helps because I am a time optimist. So, it makes a difference.”

Reflective Communication of Thoughts, Emotions and Behavior

The Headache School, accordantly to ACT, conceptualizes acceptance in three distinct forms: insight-based acceptance, behavioral acceptance, and emotional acceptance. This nuanced understanding offered patients the opportunity to accept their headache cognitively and behaviorally, while simultaneously choosing not to emotionally accept it. In doing so, patients were empowered to acknowledge the presence of the illness and adjust behavioral actions according to it without feeling obligated to be “okay” with it. One patient expressed it as: “it’s okay sometimes. It can be tough and annoying – that’s how it is.” This enabled the patients to position the headache as a more de-centralized actor in their daily lives. Many resisted full emotional acceptances, a stance still consistent with ACT’s emphasis on openness to pain without glorifying suffering. One participant summarized: “I don’t accept that I have it, but at the same time, I’ve decided that it’s not my headache that gets to decide for me.”

Negative cases also emerged, where a few participants struggled with emotional acceptance despite cognitive acknowledgment of the illness. These exceptions were retained to preserve analytic nuance and highlight variability across adaptation trajectories.

Belonging-I Did Not Have to Explain, Apologize, or Defend Myself

Group Dynamics and Community

Patients consistently emphasized the value of peer connection. Before attending The Headache School, many had encountered superficial or incomplete understanding from others, often receiving dismissive comments such as: “I get migraines too,” or “Have you tried…?”. These interactions, rooted in a lack of recognition of chronic headaches as a serious illness, left patients feeling isolated and misunderstood. Within the group, however, the shared understanding of chronic headaches as a legitimate illness fostered an atmosphere of emotional safety, validation, and connection, offering a much-needed sense of belonging and support. As captured by one of the patients: “My loneliness is gone.”

The Role of Community in Acceptance and Psychological Support

Group therapy emerged as a principal component, providing a safe space for patients to process difficult emotions and gain new perspectives through the lived experiences of others. Sharing vulnerability within the group fostered openness and helped individuals acknowledge and accept the distinct stages of their headache. This collective process proved to be a vital source of psychological support, strengthening both personal acceptance and overall well-being. One patient put this into word: “I needed to learn that there were others who felt the same way I did”.

This solidarity extended beyond the clinic. Group members supported each other in setting boundaries, especially regarding energy management. One of the patients said:

> Well, it is okay for me to say, ‘I can’t do this.’ Because I do not have as many spoons, and that is okay. That is just how it is for me…otherwise, I won’t have a good life.

Another patient stated it as: "They have to accept that sometimes you have to cancel." A third added

> It's about focusing on myself instead of everything around me, because I cannot focus on what's around me if I'm not doing well. Some might say that thinking like that is a bit selfish, but it's necessary.

These acts of boundary-setting were met with encouragement from fellow patients, reinforcing a sense of agency and mutual support.

Supportive Friendships Beyond the Headache School

All groups were encouraged to connect outside The Headache School, primarily to support each other. Many stayed connected via platforms such as Facebook. These online spaces offered forums for sharing experiences, seeking advice, and providing support. As one participant noted: "We don't talk regularly, but we have a Facebook group. Just knowing there's someone I can reach out to makes a huge difference." For many, this extended the community formed during The Headache School. Some groups also met in person, strengthening relationships and turning peer support into lasting friendships.

Group-based ACT processes, particularly shared vulnerability, validation, and social learning, appeared central for cultivating acceptance and psychological flexibility, reinforcing the value of relational contexts in persistent pain rehabilitation.

Discussion

Overall, participation in The Headache School supported patients in managing chronic headache through knowledge, acceptance, and peer support. The findings highlighted the effectiveness of ACT and the biopsychosocial approach in enabling patients lead meaningful lives despite ongoing headache. Importantly, these findings extend prior ACT research by illustrating how structured group-based education can operationalize psychological flexibility in a real-world chronic headache population. Although psychological flexibility emerged as a central mechanism, it is important to emphasize that The Headache School is a multidisciplinary and multi-component intervention. The observed changes cannot be attributed to ACT alone, but rather to the combined effects of psychological education, nurse-supported reflection, physiotherapy-guided pacing and exercise, and peer support. This integrated approach aligns with evidence indicating that complex chronic pain conditions benefit most from coordinated, interdisciplinary care rather than single-modality interventions.[41]

Knowledge and recognition constituted essential prerequisites for change. A limited understanding of chronic headache, particularly its secondary symptoms and energy constraints, had previously prevented patients from making informed adjustments in daily life, often resulting in a perceived loss of function. Many had internalized this as personal weakness, which over time contributed to a loss of identity, as also described by Nichols et al.[7] Recognizing chronic headache as a legitimate and enduring illness enabled patients in this study to move beyond a purely symptom-focused perspective and begin constructing coherent narratives about their condition. This narrative reconstruction aligns with Hydén's view of illness narratives as a means of restoring coherence and agency in the face of biographical disruption, and resonates with Jutel's argument that diagnostic labels function as narrative devices that confer legitimacy, structure experience, and shape identity.[42,43] Furthermore, The CHESS Consortium argues that the main driver for the state of coping with chronic headache was shaped by the unpredictable nature of headache severity and frequency.[44] In our study, patients similarly described navigating varying levels of energy and functional capacity, which shaped daily decision-making and reinforced the importance of pacing and value-based prioritization. In this context of uncertainty, The Headache School, provided a framework distinguishing between insight-based, behavioral, and emotional acceptance.[20] This enabled patients to acknowledge the illness cognitively and behaviorally, without being emotionally reconciled with it. Crucially, they began to let personal values, rather than the illness, guide their actions, enabling them to make deliberate, meaningful choices despite pain and fluctuating energy levels. Acceptance thus emerged as a central theme. It was not experienced as a singular event, but an ongoing, multifaceted process shaped by emotional, cognitive, and social dynamics. This aligns with sociological understandings of chronic illness, notably Michael Bury's concept of biographical disruption, which describes how the onset of chronic illness interrupts the continuity of everyday life and identity.

In this perspective, illness is not only a physical condition but also a challenge to one's self-narrative, requiring reorientation and meaning-making over time.[45] Similarly, Kathy Charmaz emphasizes how chronic illness demands a renegotiation of identity, particularly when the illness is invisible or not socially recognized. She argues that individuals must navigate the tension between their embodied limitations and societal expectations of health, normality, and productivity.[46] Through this analytic lens the presented findings could reflect these dynamics as patients described how they continuously worked to reconcile their internal experience of living with a persistent and invisible condition with the external demands of appearing "normal". Acceptance unfolded gradually, as patients redefined their sense of self while simultaneously managing how their illness was perceived by others. This dual process of internal adaptation and external presentation underscores the inherently social and identity-shaping nature of living with chronic headache. Taken together, these insights highlight the value of explicitly integrating illness education, value clarification, and metaphor-based learning tools within headache education pathways.

The use of visual metaphors such as the "Spoon Theory" enabled patients to make sense of and communicate the invisible nature of energy constraints associated with chronic headache. This supports findings from studies on chronic illness self-management, which highlight the utility of metaphor and symbolic language in facilitating mutual understanding and identity work.[47] By using such metaphors, patients were able to establish shared meaning with close relations, thereby enhancing social support while also legitimizing the need to set boundaries. This process was crucial, as the invisibility of chronic headache often make it difficult for others to grasp its impact, leading to social withdrawal and a sense of isolation.[48] This mirrors findings by Goksör et al, who also reported that a guided education can help patients reflect and express their illness experiences.[49] Verbalizing thoughts, emotions, and behaviors in The Headache School contributed to a positive feedback loop, when close relations better understood the illness, patients felt less pressure to maintain a facade of normality. Clinically, this suggests that clinicians may benefit from adopting metaphor-supported communication, particularly when treating patients with invisible or fluctuating conditions such as chronic headache.

A consistent theme among patients was the importance of feeling understood and of belonging to a group of peers with similar experiences. This aligns with qualitative studies, showing that group-based treatment for chronic pain conditions facilitates emotional connection, peer learning, and mutual feedback benefits less prominent in individual treatment settings.[50] A long-term study further supports the relevance of multidisciplinary group-based formats in generating positive behavioral changes in patients with chronic headache.[51] Patients in our study valued the group setting for its opportunities to exchange experiences, validate emotions, and engage in shared problem-solving. Consistent with this, Karayannis et al found that interventions promoting social inclusion and engagement can reduce pain-related interference in daily life, suggesting that fostering social connection may improve outcomes for individuals with chronic pain.[52] These findings reinforce the potential of group-based formats not only for skill acquisition but also for fostering social connection, which may be difficult to replicate in individual treatment settings.

Our findings indicate that The Headache School supported not only the acquisition of new knowledge but also a shift toward a broader biopsychosocial understanding of their condition. Patients revised their perceptions of the illness, recognizing it as complex and involving significant energy constraints, and began to incorporate this new knowledge into daily life. This process mirrors Kurt Lewin's change theory, which posits that sustainable change depends on both active engagement and social interaction. His work suggests that group-based learning, where participants share, reflect on, and apply new insights is more likely to produce lasting behavioral change than passive instruction.[53] This suggests that future implementation of similar programs might benefit from combining structured education, facilitated peer discussion, and guided reflection as core pedagogical components. Overall, these findings suggest that psychological flexibility may be strengthened most effectively when embedded within a supportive, multidisciplinary rehabilitation environment that acknowledges both the biological and social realities of chronic headache.

Clinical Implications and Transferability

The Headache School model may inform structured headache programs internationally by offering a replicable framework that integrates ACT principles, multidisciplinary education, and peer-supported learning. Incorporating elements such as pacing metaphors, values-based goal-setting, and guided group reflection could strengthen existing rehabilitation

pathways and enhance patient autonomy. Although developed within the publicly funded Danish healthcare system, core components of the program appear broadly adaptable to other contexts; however, cultural attitudes toward pain disclosure, access to psychological services, and reimbursement structures may influence implementation. Future research should examine how this model performs across diverse healthcare systems and cultural contexts to assess its broader applicability and scalability, including pilot implementation in other clinical settings and among patients with different headache subtypes or chronic pain conditions.

Strengths and Limitations

This study provides valuable insights into the lived experiences of chronic headache patients participating in The Headache School. The use of focus group methodology enabled rich, in-depth data collection, fostering reflection and discussion among patients. Additionally, the application of reflexive thematic analysis allowed for a nuanced exploration of themes, ensuring an iterative and flexible approach to data interpretation.[30] The inclusion of a diverse patient population, varying in headache types, socioeconomic backgrounds, and managing mechanisms, strengthens the study's ecological validity, as it mirrors the real-world complexity of chronic headache management. Furthermore, the multidisciplinary approach of The Headache School, incorporating psychological, nursing, educational, and physiotherapeutic elements, offers a comprehensive framework for understanding patient experiences across multiple domains of their daily lives.While this study offers valuable insights, certain limitations must be considered. Although the focus group format supported interaction and collective reflection, it may have constrained participants' openness regarding more private or negative experiences, potentially limiting the depth of some accounts. Although selection bias cannot be entirely ruled out, several factors suggest that the data are not systematically skewed toward favorable views. The time lag between program completion and interviews meant that participants reflected on long-term integration rather than short-term satisfaction, reducing the likelihood that only positive experiences were represented. Moreover, attrition was mainly due to headache attacks, comorbidities, or work obligations, indicating that non-participation was driven by practical rather than evaluative factors. Overall, the findings are likely to capture a broad spectrum of patient perspectives.

Conclusion

This study explored how patients with chronic headache experienced participation in a multidisciplinary, ACT-informed group program. The three themes: Knowledge and recognition, Accepting, and Belonging, together illustrate how The Headache School supported key processes of change. Patients gained a clearer understanding of the illness, developed practical and value-based strategies for living with chronic headache, and experienced a sense of community that reduced isolation and strengthened psychological flexibility. These findings demonstrate how the combination of psychological education, physiotherapy-guided training, nurse-supported reflection, and peer interaction contributes to the effectiveness of the multidisciplinary intervention and enables patients to lead meaningful lives despite persistent symptoms.

Abbreviations

CBT, Cognitive Behavioral Therapy; ACT, Acceptance and Commitment Therapy; ICHD-3, International Classification of Headache Disorders.

Data Sharing Statement

The dataset generated and analyzed during the current study is not publicly available due to the presence of sensitive interview content that may compromise participant anonymity, but the quantitative data and the thematic framework are available from the corresponding author upon reasonable request.

Ethics Approval and Consent to Participate

The study was registered at The Region of Southern Denmark (24/32787). As the study was non-biomedical in nature, formal approval from the Danish National Center for Ethics was not required for the use of interviews. This exemption is in line with the Danish Committee Act on Research Ethics Review of Health Research Projects (Consolidation Act No. 1083 of 15 September 2017, §14, subsection 2). A written informed consent was obtained from all patients before

inclusion in the study. All patients were informed that they could withdraw from the study at any time without providing a reason, and that some of their statements would be used in anonymized form in a scientific publication.

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Author Contributions

Both authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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