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Living with chronic headache: a qualitative study exploring goal management in chronic headache

Yvette Ciere, Annemieke Visser, Bram Jacobs, Marielle Padberg, John Lebbink, Robbert Sanderman & Joke Fleer

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Introduction

Balancing multiple goals in the pursuit of a meaningful life is a familiar challenge for many people. For people with chronic headache (CH), who suffer from headache on at least 15 days per month for a period of three months or longer, this challenge may be even greater [1]. Indeed, evidence suggests that headache and pain in general can disturb goal pursuit, for instance, by limiting the attainability of personal goals or creating conflict between multiple goals [2–4]. In turn, greater disturbance to personal goals has been associated with higher perceived disability [2,3,5]. Goal disturbance has furthermore been found to predict greater pain severity in daily life [6,7], suggesting a possible downward spiral of increasing headache and disability.

Accumulating evidence in non-headache chronic pain conditions, however, suggests that the extent to which people experience pain-related disability depends on the way in which they manage goal-related limitations [8–10]. The dual process model (DPM) distinguishes two types of strategies to manage limitations to goal pursuit: assimilative and accommodative strategies [11,12]. Assimilative strategies are aimed at adjusting the situation in the service of personal goals [11]. In the context of pain, such strategies may be focused on removing pain itself, but also on adjusting daily activities such that they can be continued in the presence of pain [10]. In contrast, accommodative strategies are aimed at adjusting goals to situational constraints [11]. This may include disengaging from goals that are blocked by pain, which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.
and reengaging in meaningful goals that are attainable despite pain [10].

The DPM assumes that both types of strategies can be adaptive, depending on the situation in which they are used [11]. That is, assimilative strategies are effective as long as people are able to control situational factors that interfere with goal pursuit; when control is low, a switch to accommodative strategies can be necessary. Chronic pain presents a situation in which control is typically low: pain is often unpredictable and difficult to resolve or control by medical intervention. Accommodative strategies may in this situation be beneficial. Indeed, several studies have shown that persistence in assimilative strategies is associated with higher pain-related disability, while the use of accommodative strategies is associated with lower pain-related disability [8–10,13].

Most studies on goal management in chronic pain to date have used a quantitative approach, and have mainly focused on general tendencies to use assimilative and accommodative strategies. As a result, there is a lack of insight into the nature of goal-management in the context of specific chronic pain conditions, such as CH. Yet, gaining insight into how individuals with a specific chronic pain condition manage their goals may help clinicians to recognize and address problems in goal management when they encounter them in clinical practice. Qualitative research designs are highly informative in answering such questions as they give insight into how people think and act in everyday life and how this depends on their context [14].

The current study used a qualitative approach to study how people manage their personal goals in the context of CH. We examined (1) which goal management strategies are used by individuals with CH, and (2) how they experience the process of goal management. Based on the DPM, we expected that the goal management strategies employed by CH patients could be distinguished in assimilative and accommodative strategies. Furthermore, we hypothesized that assimilation would be the strategy of first choice, and that accommodation would be employed in the context of low control.

Method

Design

This study used a qualitative research design, based on a method developed by Hennink, Hutter and Bailey [15]. This method combines inductive strategies (i.e., reflecting on the data collected) with the use of deductive strategies (i.e., the use of existing theory). This approach allowed us to empirically examine the application of the DPM [11] in the specific context of CH, as well as to identify headache-specific themes that were not covered by this theory.

Participants

Purposive sampling was used to recruit CH patients of varying age, gender, and diagnosis. Patients were recruited from three neurology outpatient clinics in the North of the Netherlands and via the Dutch Society for Headache Patients. Patients were informed about the study via information letters distributed by neurologists at the outpatient clinics or posted at the website and social media accounts of the patient society. The information letters contained information about the goal of the study, the study procedure, and mentioned that any travel expenses would be reimbursed.

Interested patients were contacted by the researcher (Yvette Ciere) for further information and screening. Eligible patients were 18–75 years old and were diagnosed with chronic migraine, tension-type headache or medication-overuse headache. At the moment of inclusion, headache had to be present on 15 or more days per month in the past 3 months (in accordance with the diagnostic criteria for CH [1]). Patients were excluded when first onset of headache was less than a year ago, when they reported another co-morbid headache disorder (e.g., cluster headache) or when they were insufficiently able to express themselves in Dutch. In patients recruited from the neurology clinics, the headache diagnosis was established by a neurologist. Patients recruited from the patient society where only included if their headache diagnosis had previously been established by a neurologist.

Patients were instructed that data would be stored and reported anonymously, that participation was voluntary and that they could withdraw from the study at any time. All participants provided written informed consent. The medical ethical board of the University Medical Centre Groningen waived the need for full ethical review.

Procedure

Participants took part in a one-time semi-structured interview (interview schedule is available on request) at their home or in the research department of the University Medical Centre Groningen. Interviews were conducted by the first author (YC) (N = 14) or a trained research assistant under supervision of the first author (N = 6). The interview schedule contained a standardized instruction about what goals are as well as pre-defined questions about participants’ goals, strategies used to cope with barriers to goal pursuit (assimilation), and strategies used to adjust goals to CH-related limitations (accommodation). Examples of interview questions are: “What are your current goals?”, “How do you try to achieve [goal X], despite your CHs?”, “In which way have your goals/priorities changed as a result of having CHs?”. The interviewers asked further questions in response to the participant’s answers to gain a deeper understanding of the topic. Duration of the interviews ranged between 38 and 68 min. All interviews were audio-taped. Field notes were made after the interviews to aid data analysis. Since the last interviews did not yield any new themes (i.e., saturation was reached), data collection was completed after 20 interviews.

Data analysis

To establish trustworthiness, three researchers were involved in all steps of data analyses. Researchers were a health psychologist who performed graduate research on CH (Yvette Ciere), a senior researcher in applied health sciences with qualitative research experience (Annemieke Visser), and a senior researcher in health psychology with expertise in goal management in the context of chronic disease (Joke Fleer). The first five transcripts were independently coded by two authors (Yvette Ciere and Annemieke Visser), after which discrepancies were resolved through discussion and consultation with a third author (Joke Fleer). The remaining transcripts were coded by Yvette Ciere and randomly checked by Annemieke Visser. Data were analyzed using a thematic analysis method [16]. We followed the six steps described by Braun & Clarke [16]: (1) transcribing the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining themes, and 6) producing the report.

Steps 1 and 2: transcribing data and generating initial codes – Interviews were transcribed verbatim and anonymized. An initial list of potential codes was produced by searching the extant literature on goal management [17–19]. Two authors (Yvette Ciere and Annemieke Visser) then closely read five transcripts to check whether these codes fit with quotations that were relevant to our
research question. Codes that were not represented in the data were discarded from the code list. Data were also searched for quotations that did not fit into one of the codes on the initial code list, but were nevertheless relevant for answering our research questions. This open coding yielded new codes concerning the context and consequences of goal management. The final list of codes was used to label relevant quotations in all transcripts. When new issues emerged during coding, these were added to the code list and checked for presence in all transcripts. Data were coded using ATLAS.ti [20], a software package that supports qualitative data analysis.

Steps 3 and 4: searching for themes and reviewing themes – The identification of broader themes (i.e., patterns in the data) was performed in several iterative steps [15]. Throughout these steps, hypotheses were generated by analyzing a subset of the data and then validated and deepened by checking data of the remaining participants. First, initial themes were developed by sorting codes into meaningful categories and displaying these categories in a thematic map. Second, the validity of initial themes was checked by examining whether all quotations within a theme were consistent and whether themes occurred in more than one participant. Third, we examined the story within and across themes by producing descriptions of the themes for each participant and by comparing these descriptions across participants as well as with theory on goal management.

Steps 5 and 6: defining themes and producing the report – After agreeing on the themes and the overall story of the data, we drafted a description of each theme and identified representative quotations for each theme. Finally, we wrote an analytic narrative of the story of the data, using a case example to illustrate the essence of this story.

Results

Participants

Table 1 presents characteristics of the participants included in this study (N=20). The average age was 38 (19–72) years. The majority of the sample was female (80%), in a relationship (75%), had no children (63%), and had obtained an associate’s degree (35%) or bachelor’s degree (30%). Eleven participants (55%) reported having chronic migraine, seven a combination of chronic tension-type headache (CTTH) and episodic migraine (35%), two CTTH alone (10%), and one nummular headache (5%). Six participants (30%) reported a co-morbid condition (e.g., chronic fatigue, COPD) that also interfered with goal pursuit. However, in all these cases, CH was the most prominent health complaint.

Goal management strategies

Goal management in CH was found to involve the maintenance of a balance between resources and the goals demanding these resources. For most participants, this was a challenge as headache did restrict the amount of available resources. As headache increased, the amount of time or energy available for goal pursuit typically decreased, limiting progress towards goals or causing greater conflict between goals. For instance, many participants struggled to continue both work and social activities, given that the first drained most of their resources.

On one side of the balance, assimilative strategies (i.e., strategies in which the context is adjusted in service of a goal) were used to manage the resources needed for the engagement in personal goals. Importantly, some of these strategies used resources (“resource-depleting strategies”), whereas others saved or restored resources (“resource-replenishing strategies”). For instance, persisting activity in the presence of headache burned resources, whereas adjusting planning helped participants to save resources. Note that medication use was labeled as a resource-depleting strategy, as most participants employed this strategy to persist in goal-directed activities, which resulted in greater energy depletion in the longer term. There are however also possible situations in which medication use could restore resources, for example when it helps patients to sleep better.

On the other side of the balance, accommodative strategies (i.e., strategies in which goals are adjusted to situational constraints) were aimed at regulating the goals that demanded resources. A large imbalance between goals and resources could result in greater perceived disability or more severe headache. Indeed, most participants tried to regain balance through the use of accommodative strategies, which could be distinguished in “goal disengagement” and “goal re-engagement” strategies. Goal disengagement involved letting go of or scaling back goals that used a disproportionate amount of resources, which was often the case for achievement-oriented goals such as work- or education-related goals. Goal re-engagement involved adopting or prioritizing other meaningful

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<td>Student</td>
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CTTH: chronic tension-type headache; CM: chronic migraine; EM: episodic migraine.
goals. Typically, these were less demanding or more flexible goals (e.g., distant learning, voluntary work).

All participants were found to use assimilative strategies, but differed in the extent to which they combined resource-depleting and resource-replenishing strategies and thus maintained a good balance. In fact, some participants saw the use of resource-depleting strategies as the only way to continue with meaningful activities. The majority of participants also reported the use of accommodative strategies. Goal disengagement strategies were the most frequently used accommodative strategies, but some patients also used goal re-engagement strategies. These appeared to be patients that had given up highly important goals and could not replace these with existing goals.

A description and example quotes of the reported goal management strategies are presented in Table 2.

### The process of goal management

Although we found that the majority of participants eventually used a combination of assimilative and accommodative strategies, most participants reported that their strategy use had changed over time. Most participants reported that they initially focused on the use of resource-depleting assimilative strategies, as a way to hold on to important goals (a phase we called "persistence"). However, as this approach typically resulted in a depletion of resources, and thus greater disability, most participants told us they were eventually forced to apply accommodative strategies ("reorientation"). After regaining balance as a result of accommodation, some participants reported that they tried to keep this balance by combining resource-depleting and resource-replenishing assimilative strategies ("balancing"). The next sections give a description of these phases illustrated by the example of "Lisa" (32-year old female, researcher). Please note that these results were derived from retrospective reports and should therefore be interpreted with some caution.

### Persistence phase

**Case “Lisa”**. Lisa’s tension-type headaches and migraines started when she was 13 and aggravated during her studies. Starting her first job, Lisa was eager to leave a good impression and gratefully accepted extra tasks, even though the extra hours exhausted her. By that time, she had daily headaches and weekly migraine attacks. However, Lisa believed that whatever she did, she was not able to control her headaches. Hence, she went to work regardless of how much pain she had (persistence activity in the presence of symptoms). Outside of work, Lisa spent most of her time playing with her band. Making music was her true passion and she rather took extra painkillers than to cancel a band practice (resource-depleting assimilative strategy “using medication”). Although her neurologist had warned her for the risks of taking too much pain killers, Lisa saw this as the only way to live a meaningful life despite her CHs.

In the “persistence phase,” participants predominantly used resource-depleting assimilative strategies to be able to hold on to valued goals despite the (often increasing) interference of CH. A large proportion of resources was typically invested in the most demanding goals. Often these were goals related to work or school activities as these allowed for less scheduling flexibility, came with a feeling of responsibility, or were needed to achieve more abstract goals such as “contributing to society” or “developing oneself.” Participants also mentioned that factors such as being perfectionistic or perceiving a lack of understanding from others (e.g., co-workers) played a role. Because most resources were spent on the most demanding goals, participants reported having fewer time or energy left for other goals, such as family or social activities. As a result, they frequently worried about having to cancel these activities, or felt guilty or frustrated for having to do so.

Many participants were highly dependent on pain medication to keep up with all demands. Often, they did use more than the prescribed dose of medication, despite being aware of the risks of medication-overuse. Some participants actively searched for other ways to resolve headache, such as medical procedures or alternative treatments. Although these attempts to control pain were effective in the short term, they also appeared to limit energy reserves even further. Irrespective, some participants reported that they continued “fighting headaches”, as they were convinced that “giving in to headache” would make them feel even more disabled.

### Reorientation phase

**Case “Lisa”**. After a stressful period at work, Lisa was diagnosed with a burn-out. She realized that her strategy to just keep on...
going eventually backfired, and that she had no other option but to listen to her body better. Together with a work coach, she reconsidered the role of work in her life. Although work remained important to her, she decided it should not come at the cost of her health (prioritizing health). Hence, instead of continuing to say ‘yes’ to every request, she decided only to focus on what was most important to her: meaningful teaching and expanding her knowledge (re prioritization). Furthermore, Lisa gave up on her goal of playing in a band (giving up goals). Instead, she decided to pursue her passion for music by going to concerts together with her partner (adopting alternative goals).

Most participants stayed in the persistence phase for many years. For the majority of patients, the continuous depletion of resources culminated in high disability and serious health problems such as a burn-out, depression, or medication-overuse headache. This was generally a “turning point” at which participants became aware of the need to change their approach.

After the turning point, participants moved to a “reorientation phase” in which they used accommodative strategies to obtain a better match between their goals and resources. This was often experienced as a difficult process, which required participants to accept the limitations of having a chronic condition. Goals that were adjusted or given up were often major goals such as a career, a highly valued leisure activity, or the desire to have (more) children, which naturally elicited feelings of sadness or grief. Nevertheless, patients realized the need to “make room for headache” in their life. Having less demanding goals eventually reduced the constant confrontation with limitations, lowering feelings of stress and frustration. Some participants also noticed physical improvements such as feeling more energetic and having less headaches.

Importantly, the disengagement from goals also meant that participants had to find new ways to give their life meaning. For instance, one participant explained that she had felt empty and needed to reinvent herself after giving up important goals. Hence, some participants (re)-engaged in new goals. Some of these goals were specifically aimed at regaining health or balance. Others provided an alternative path to attain more abstract goals such as “helping others” or “developing oneself.” For instance, paid work was replaced by voluntary work or a leisure activity.

Balancing phase

Case “Lisa.” Nowadays, Lisa’s daily routine looks a lot different. She spends most of her time at work on tasks that are truly important (prioritizing activities). When she feels a migraine coming up, she has enough room in her schedule to go home early or take a day off (adjusting activities). At first, it was difficult to say “no” to her colleagues, but Lisa now feels strengthened by the fact that these small adjustments greatly improved her productivity and work satisfaction. In addition, Lisa plans fewer activities outside of work so she has more time to rest (adjusting planning). Although finding a good balance between taking care of her health and doing the things she likes is a constant challenge, Lisa feels at least she has a stable foundation now.

In the “balancing phase,” participants tried to maintain balance by adopting resource-replenishing assimilative strategies. Participants learned to better monitor their energy level and use strategies to save or restore energy. For example, one participant told us that a physiotherapist had taught her to adjust her schedule on days at which she was more sensitive to external stimuli (e.g., loud noises). Although participants still used energy-depleting strategies (e.g., persisting activity), they appeared to be more selective in when they used these strategies and balanced this with the use of energy-replenishing strategies. For example, a participant explained how she would use medication to be able to go to an important appointment, but then took more rest later in the week.

While this collection of strategies helped participants to maintain a better balance, their use did require a large amount of flexibility in the pursuit of daily activities. Because of fluctuating headache severity and energy, participants had to be constantly aware of their limits and needed to be willing to adjust or sacrifice planned activities. Some participants described this as a constant tradeoff between engaging in activities and acknowledging the limitations of CH. However, participants also noted positive consequences such as being better able to appreciate the little things, being more empathetic towards others, and having closer relationships with others. Most importantly, they felt able to live a meaningful life despite their CHs.

Discussion

The aim of this study was to explore how people manage their personal goals in the context of CH. Participants were found to use a combination of assimilative and accommodative strategies to regain and maintain a balance between personal goals and available resources for goal pursuit. Furthermore, their retrospective reports suggested a development in strategy use over time. We distinguished three phases: the “persistence phase,” characterized by the use of resource-depleting assimilative strategies, the “reorientation phase,” characterized by use of accommodative strategies, and the “maintenance phase,” involving the use of both resource-depleting and resource-replenishing assimilative strategies.

The finding that people use assimilative and accommodative strategies to manage CH-related limitations to goal pursuit is in line with the Dual Process Model and research in other chronic health conditions [11,21,22]. It should however be acknowledged that use of the DPM as an explicit framework for this study may have steered our findings. Participants reported a broad range of goal management strategies, which appears in line with literature suggesting that flexibility in strategy use is necessary for managing changing situational demands and constraints [23,24]. To our knowledge, we are the first to distinguish two types of assimilative strategies: resource-depleting and resource-replenishing strategies. This may be a clinically useful distinction, as it suggests that patients may maintain balance, and potentially prevent further disability, by using a combination of these strategies. However, this hypothesis needs testing in future quantitative studies.

The finding that most participants reported that they first used assimilative strategies before switching to accommodation is in accordance with the DPM, which suggests that such a switch typically occurs when opportunities to control the situation are low [11]. A noteworthy finding, however, was that many patients only made this switch after developing serious complications such as a severe aggravation of symptoms, burn-out, or depression. This finding appears to provide context to earlier qualitative studies in other chronic pain conditions identifying persistence in assimilation as a risk factor for pain-related disability [8–10,13]. Also in line with these earlier studies, findings suggest that accommodating goals to the constraints of CH allows for more flexible goal pursuit. Accommodation may thus be an important focus of treatment for patients with high levels of disability.

Previous studies have already demonstrated that CH has a large impact on daily life, affecting a broad range of life domains [25–27]. An earlier qualitative study showed that headache may
even impact on perceptions of self [28], which seems to concur with our finding that some patients had to give up goals that were central to their identity (e.g., career, wish to have children).

Importantly, this study shows that patients engage in a number of active strategies to reduce the impact of CH on daily life and identity, but that some of these strategies may eventually cause greater disability. A study by Jonsson et al. [29] showed that one of these strategies, the overuse of acute medication, can in fact be perceived by patients as the only way to prevent headache from ruining their lives. Interventions aimed at reducing medication overuse may thus need to focus on helping patients to find other ways to pursue goals despite CH.

Several methodological limitations need to be acknowledged. First, the goal management phases were identified from retrospective reports and thus need confirmation in future prospective studies. Second, as chronic migraine (CM) is typically associated with higher disability than chronic tension-type headache (CTTH) [30], it is plausible that patients with these conditions differ in their use of goal management strategies. However, as most participants with CTTH also suffered from episodic migraine, we were unable to compare between these groups. Third, although none of the participants reported a formal diagnosis of medication overuse headache (MOH), the diagnosis of patients recruited from the patient society was not confirmed by a neurologist prior to inclusion. It is therefore possible that cases of MOH were missed. As MOH is a condition that could potentially impact on goal management, it would be preferable to exclude patients with MOH or compare between those with and without MOH in future studies.

Notwithstanding these limitations, this study highlights a number of directions for future research. First, as our findings suggest that goal management is associated with headache-related disability, future studies may investigate the relationship between goal-management strategies and headache-related disability over time. Such studies may also examine the role of goal management in the transformation from episodic to CH, as some patients reported that persistence in assimilative coping was accompanied by an increase in headache frequency. Another topic for further study are the processes that enable the switch from assimilation to accommodation. One of these processes may be pain acceptance, i.e., the willingness to experience pain and engage in meaningful activities despite pain [31,32]. Acceptance and accommodative coping have been related in previous studies [9,33], but the direction of this association is still unclear. It could be that accepting headache as part of life is a prerequisite for the adjustment of goals to limitations. Alternatively, setting attainable goals may promote acceptance by reducing the need to “fight” headache.

Our findings highlight several opportunities to improve daily functioning in individuals with CH, by intervening on goal management processes. First, results suggest that disability may be prevented by promoting adaptive goal management strategies and preventing persistence in assimilative coping. Cognitive–behavioral interventions may support patients in setting attainable goals and managing resources effectively (e.g., by finding a good balance between activity and rest). Second, patients with high levels of disability may benefit from support in adjusting goals to the limitations of CH. Acceptance-based cognitive therapies, such as Acceptance and Commitment Therapy [34], may for instance guide patients in coping with the negative emotions resulting from giving up important goals and in identifying meaningful alternatives [35].

The present findings contribute to a better understanding of CH-related disability and the pathways that may lead to improved functioning. Persistence in the use of resource-depleting strategies as a way to keep headache from interfering with goal pursuit was found to be associated with greater headache-related disability. In contrast, a more flexible goal management approach, in which goals are adjusted to the limitations of CH, was found to be associated with better functioning. These findings could inform the development of interventions aimed at improving functioning and quality of life in CH. They also highlight the need to examine the relationship between goal management and disability in further quantitative research.

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