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Coping and Motivation for Change—An Interview Study of the Experience From Participation in an Educational Program for Patients With Medication-Overuse Headache

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Abstract

Patient educational programs (PEP) are recommended as part of the treatment for medication-overuse headache (MOH), however, knowledge of patients' experiences when participating is sparse. This study explored how patients experienced participating in a PEP focusing on empowering coping strategies and motivation for behavioral changes. Eight individual semistructured interviews were conducted among patients suffering from MOH who had attended a PEP intervention in a randomized controlled trial. The PEP involved techniques from Motivational Interviewing as its communicative approach. Data collection, analysis, and interpretation were performed within a phenomenological-hermeneutic framework. Results showed that patients found the educational program relevant regarding coping with headache. Participants shifted from focusing on medication to include other ways to manage headache. Experiences regarding ambivalent feelings for behavioral change and feelings of stigmatization were key issues. Participation in this PEP helped the participants cope with headache in new ways relevant to their everyday lives and challenges. The individualized approach enabled by Motivational Interviewing was experienced as useful by the participants, as it actively involved them in the treatment.

Keywords

behavioral health, communication, patient education, qualitative

Introduction

Pain management can be challenging and a frequent intake of medication for pain relief may become a pain-coping strategy (1). For headache patients, the excessive use of pain medications may lead to the development of medication-overuse headache (MOH) (2,3). The International Classification of Headache Disorders, Third Edition, define MOH as a chronic secondary headache occurring $\geq$15 days per month, caused by a regular overuse of acute or symptomatic headache medication (3). The medication overuse represents a harmful behavior that indicates a lack of control which can become a vicious cycle due to escalation of the headache pattern. Psychological factors may adversely affect the overuse of medication (4), but also other multidimensional interrelated factors contribute, for example, type and severity of the primary headache diagnosis and which drugs are overused (5). This makes MOH an exceedingly heterogeneous disorder. Patients with MOH frequently report adverse

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effects of their headache on work-life, social acceptance, and lack of feeling of control over the headache (6). Since many aspects of the patients' lives are affected, MOH is considered a disorder where emotions and pain are intermingled (7). Hereby, the management of headache becomes strongly influenced by behavioral factors (8), leading to a conceptualization of MOH as a biobehavioral disorder (4,9). Therefore, the treatment will benefit from involving both pharmacological and nonpharmacological approaches. The primary pharmacological approach to cure MOH is withdrawal of the overused medication. Unfortunately, the pharmacological approach fails to take the behavioral and emotional components into account, although there are strong indications that these factors affect treatment in headache patients (9). Hence, it is recommended that treatment of MOH should consist of withdrawal of medication combined with a patient educational program (PEP) in order to empower emotional and behavioral factors of the treatment (4,5,10–13). In this study, PEP is defined as an education for patients with MOH focused at motivation for behavioral change and reinforcement of coping strategies (4).

One way to increase patients' motivation through education could be to apply Motivational Interviewing (MI). Motivational Interviewing is developed by Miller and Rollnick (14) and is theoretically inspired from several authors, among them Prochaska and DiClemente's behavior change theory (15) and Roger's nondirective counselling (16). Through conversation, patients are expected to clarify possible ambivalences with respect to behavioral changes, with a focus on becoming aware of their own motivation for change and use of coping strategies to manage headaches and avoid recurrence of MOH (14,17).

Several studies have focused on the patients' experience with treatment of migraine (18–20) or chronic headache (21–28). Findings from a qualitative study on migraine patients who had participated in a behavioral intervention showed that the patients applied the interventional elements after the intervention. The patients selected the elements they found most beneficial and incorporated them into their daily lives to manage and prevent migraine (27). From a systematic review regarding patients' experiences of living with chronic headache, 3 overarching themes: Headache driver for behavior, Spectre of headache, and Strained relationships were identified (28), which potentially can be targeted through PEPs. Studies focusing on the patients' needs and perspectives on education are important to reach an understanding of the optimal content of PEPs. However, when it comes to MOH, there is a lack of knowledge regarding the patient perspective on needs and perspectives on PEPs. Thus, the aim of the study was to provide in-depth insight in and understanding of how MOH patients experienced participating in a PEP focusing on coping strategies and on individual motivation to implement behavioral changes.

Methods

This qualitative study was embedded in a randomized controlled trial (RCT) (29) aiming to explore the effect of a PEP based on the communicative approaches from MI. Patients were enrolled in the RCT study for 9 months, and outcomes were measured at baseline, after the 12 weeks of educational program, and at 9 months follow-up. Patients were randomized either to standard treatment and the 12-week educational program ($n = 48$) or to standard treatment alone ($n = 50$). The participants allocated to the educational program chose whether they wanted to receive the PEP as individual sessions or in a group consisting of 5 to 8 participants. Regardless of setting, the content of the PEP was the same. The rationale behind offering 2 different possibilities of delivery were that MOH patients represent a heterogenic group and a belief that "one-size-does-not-fit-all." Suffering from chronic headaches may influence patients' surplus and inclination to join a group, resulting in a less beneficial outcome from the educational program. Conversely, some individuals benefit more from participation in groups due to the possibility of being able to exchange experiences and strategies with other patients in a similar situation. Interviews were performed in average 2 years after participation in the RCT study (29).

The design of the present study was guided by a phenomenological-hermeneutic approach to analysis and interpret patients' experiences from participating in a PEP (30). Individual semistructured interviews were conducted. The purpose of the interviews was to gain an understanding of the phenomenon, as understood by the interviewed person, bracketing the interviewers own preunderstanding (30). Prior to the interviews, the authors developed a semistructured interview guide based upon a literature search and the aim of the study. The overall areas of interest were experiences from participation in the PEP, motivation for behavioral changes, and coping strategies related to headache and medication. In this study, coping was understood as constantly changing cognitive and behavioral efforts to manage external and internal demands, which are experienced as challenging or exceeding the resources of the person (31).

Setting and Participants

We used convenience sampling (32). Eligible patients were aged 18 to 65 years and had participated in the RCT. The RCT participants, who still received active treatment 2 years after attending the PEP ($n = 14$), received detailed information about the study by letter or at routine consultations at the Headache Clinic and were invited to participate. We aimed at maximum variation in age, gender, and whether the patient had participated in PEP delivered in individual or group sessions in the RCT (33).

Table 1. The Educational Content of the 6 Sessions in the PEP.[a]

Themes	Agenda	Exercises
Session 1	■ Introduction ■ Presentation of overall educational structure ■ MOH + patients' own stories ■ Brief introduction to MI ■ Patient involvement when working with changing behavior	Three function model Active listening PEARLS for good communication (Relationship to the patients build on; Partnership, Empathy, Acknowledgement, Respect, Legitimation, Support)
Session 2	■ Introduction to the model stages of change ■ Clarity of the importance and ability to change behavior	Stages of change: Identification of own stage according to the model Rating importance and ability to change (VAS scale)
Session 3	■ Theory on life values ■ Introduction to feelings of ambivalence ■ How to be aware of pros and cons with respect to behavioral changes	Working with life-values, How do they fit with behavioral choices?
Session 4	■ Changing theory/mechanisms ■ Future: what to aim for? ■ Introducing the story of Peter Pan, as an example of always longing for something else	Exercise on success: what do patients define as a success criterion
Session 5	■ Resources and inner strengths. Reflections on how and when these can be a force and when to be aware of disadvantages	Resource cards—pick 3 cards defining your strengths. How can these strengths be used to change behavior? Reflections in plenum
Session 6	■ Challenges for behavioral changes ■ Which objective to achieve and how to get there ■ Patients' evaluation on the educational program	Challenges when working with behavioral changes goal setting

Abbreviations: MI, Motivational Interviewing; MOH, medication-overuse headache; PEP, patient educational program; VAS, Visual Analogue Scale.
[a]Focus in the PEP was on coping strategies to manage headache without medication overuse and on the patients' motivation to maintain a changed behavior without extensive medication use after withdrawal of the medication. The PEP intervention consisted of 6 sessions every second week for 12 weeks. Each of the sessions was designed with a mix of conversation and cognitive exercises to promote behavioral changes, using altered coping strategies for managing headaches. The PEP content was described in detail to streamline the education for all participants and consulted with a psychologist specialized within the MI techniques. The patients chose whether they preferred to receive the PEP as individual sessions, with nurses specialized in headache disorders as educators, or in groups of 5 to 8 participants, led by a headache nurse and a physiotherapist specialized in headache disorders. Although the PEP content was the same regardless of educational setting, the duration differed, as individual sessions lasted 1 hour, while group sessions lasted one and a half hours.

The PEP

The PEP consisted of 6 sessions within 12 weeks. The content was a mix of dialogue and cognitive exercises to promote behavioral changes and altered coping strategies to manage headache. The PEP was facilitated by nurses and physiotherapists from the Headache Clinic and is described in detail elsewhere (29). A short overview of the content in the PEP is provided in Table 1.

Data Collection

The second author who is a nurse and trained interviewer conducted all the interviews in October 2017. The interviews took place either in a room at the hospital or in the participants' private homes, depending on the participants' preferred location. All interviews were audio recorded and lasted 30 to 40 minutes each. Prior to the interviews, the interviewer had participated in 2 of the group sessions in the PEP to gain insight into the themes and the setup. In accordance with the phenomenological-hermeneutic approach, the interviewer tried to remain open to the participants' views and experiences and put own preunderstandings aside during the interview. The interviewer started with open questions such as, "Could you try to tell me how you experienced participating in the PEP? and "How do you manage your headache now? Probing questions such as, "Can you elaborate a little more on that" were used to explore the participants' experiences further. This approach gave the participants a chance to elaborate on statements or elements of importance for them.

Data Analysis and Interpretation

All recorded interviews were transcribed verbatim. The transcriptions were analyzed systematically by the authors initially in a 5-step phenomenological coding approach inspired by Kvale and Brinkmann (30) providing themes regarding participation in the PEP (Table 2).

The hermeneutic approach led to interpretations of the descriptions and addressed the themes from the analyses in 3 interpretational contexts; "self-understanding," "critical common sense understanding," and "theoretical understanding" (30). Self-understanding expressed the participants' rephrased and condensed statements. In the context of critical commonsense understanding, the interpretation went beyond self-understanding and included general

Table 2. The 5-Step Analytic Process Conducted by the First and the Second Author.

1. Step: Holistic reading of the interviews
   Initially, all 8 transcribed interviews were read several times by the second author to provide an overall impression of the interviews.
2. Step: Identification of natural meaning units
   Initial coding of all-natural meaning units related to the patients' narrated experience was identified.
3. Step: Formulation of initial themes
   The identified natural meaning units were reformulated in short by the researcher, as simple as possible, to put the patients' statements into initial themes according to the research aim.
4. Step: Linking themes
   The initial themes were linked between transcripts, looking for differences, similarities, and patterns.
5. Step: Overall themes
   Finally, the initial themes from the interviews were condensed into more overall themes.

Table 3. Characteristics of the Included Patients.[a]

	P1	P2	P3	P4	P5	P6	P7	P8
Age (years)	57	64	41	32	31	34	57	48
Gender	♀	♂	♀	♂	♂	♂	♀	♂
Married/cohabiting	+	+	+	-	+	+	+	+
Employment	+	-	+	-	+	-	+	-
Headache duration (years)	13	54	8	17	15	3	25	19
Intervention group	Grp	Ind	Grp	Ind	Grp	Ind	Grp	Ind
Sessions attended	6	6	4	6	6	6	4	6

Abbreviations: Ind, individual education; Grp, group education; Attended, the numbers of sessions the patients attended in the PEP; ♀, men; ♂, women.
[a]The included patients are anonymized by codes (P1, P2, etc to P8).

knowledge which enrichened the condensed statements. In the third context theoretical understanding, the findings were discussed in the light of existing literature and theories (30). Within the phenomenological-hermeneutic approach, there is not only one way to interpret a text (30). To validate the analyses, the authors were vigilant to recheck the transcriptions to verify that the interpretations were rooted in the participant shared experiences. Furthermore, repeatedly the analytic steps were discussed among the authors to ensure that the interpretations reflected the experiences described by the participants.

Results

Fourteen participants were invited to participate, 8 (57%) accepted, while 6 did not respond. The 8 participants consisted of 3 men and 5 women aged 31 to 64 years. In Table 3, characteristics of the participants are presented. Based on the preference of the participants, 3 of the interviews took place in a room at the hospital and 5 in the participants' private homes.

The analyses derived 3 themes: (1) changing coping strategies after participating in the PEP, (2) self-perception and feeling of stigmatization, and (3) experience of motivation for behavior change during participation in the PEP. The themes are presented in short in Table 4.

We elaborate on the themes in the following section and have selected direct quotations from the interviews to illustrate the findings. The quotations were deidentified by codes for each participant (P1, P2 etc to P8).

Changing Coping Strategies After Participating in the PEP

The interviews showed that the participants found it important to take responsibility and make an effort themselves regarding treatment of their headaches. One of the participants said:

> I would really like to do something in order to feel better. Earlier, I would take a pill to get better, so it's best if I do something different from that, something else. Because otherwise I feel like I'm doing nothing – just accepting that I feel awful – and I don't want that. (P8)

Lack of own effort to manage the headache was associated with the experience of lost control which entailed that almost all participants spent a lot of energy thinking about the occurrence of the next headache attack and how to manage their headache actively. The headache, therefore, played a central role in the participants' awareness and the way in which they acted in their everyday lives. Before they started withdrawal from medication and subsequently, attended the PEP, their preferred action to manage headache was the use of medication, that is, they used medication as a coping strategy to try to gain control over their headache. During participation in the PEP, the participants' focus shifted from the pharmacological treatment toward other ways to control their headache. This turned out to be a beneficial strategy. After withdrawal of medication and participation in the PEP, they expressed relief because the focus was no longer on medication "It is a relief no longer considering medication" (P2). The participants experienced that they had developed altered coping strategies, such as to use positive thinking and accept the headache attacks. Especially, the acceptance of the headache seemed to illustrate a meaningful new coping strategy. One of the participants said:

Table 4. Overview of the Derived 3 Themes and Their Associated Subthemes.

Themes	Subthemes
Changing coping strategies after participating in the PEP	• Management of own treatment • Controlling headache in new ways • Shifted focus from medical treatment
Self-perception and feeling of stigmatization	• Increased self-efficacy throughout the PEP • Ambivalent emotions regarding changed behavior • Ambiguous self-perception
Experience of motivation during the PEP	• Active participation in the PEP • Relevant patient-centered approach

Abbreviation: PEP, patient educational program.

> Previously, I got extremely frustrated when the headache destroyed my day (. . .) Now, I think positive thoughts and I try to change my focus to something else. I am convinced that I manage to get through this, and I find some kind of inner strength. I have found a new way of thinking and I have found peace of mind. (P4)

After attending the PEP, most of the participants expressed a fundamental belief that they were now able to cope with their situation without an extensive use of headache medication. One of the participants described:

> Well, when I get migraine attacks, then that's just how it is. Now I can easily manage- it's still extremely difficult but now I know that I won't die from migraine. I don't know. If I hadn't had these conversations with 'x' (the nurse in the course), I'm not sure I would handle the headache the way I do now, where I can easily get through it without taking medication. (P4)

Self-Perception and Feeling of Stigmatization

The participants seemed to increase their belief in the ability to be able to cope with headache without excessive use of medications. Although all the participants expressed motivation for behavioral changes regarding the management of the headache, some were also challenged by ambivalent emotions about the future management. It was a challenge to abstain from medication when having a severe headache. One participant said:

> I mean, you really need to be focused on not taking any medication. You cannot have any medication at home, because then you might easily just . . . (. . .) But, as you know, I have made a decision that I won't do that." (P8)

This statement was further supported by another informant:

> The biggest challenge of not taking medication, well, it's still there. It's when everything is difficult (. . .) It's a constant challenge (. . .) I could just take three pills. And that challenge is still there (. . .) Cause I can easily buy them over-the-counter. (P3).

From the PEP, the participants had learned that the constant inner dialogue and outweighing pros and cons for coping differently with the headache were highly relevant, as they reflected upon the choices they made.

They were aware that their previous drug consumption had been large, but they felt it had been necessary. In contrast, however, several participants used words related to addiction during the interviews, when they referred to their own situation. "I consider taking too many pills is a bit like drinking or doing drugs" (P3). The descriptions, therefore, seemed ambiguous when they tried to link their self-image to overuse of medication. A patient elaborated:

> I would like to admit that I took a lot, but I have never had an addiction . . . In the beginning, me and my family joked about addiction and that I should attend AA meetings and confess. Afterwards, I felt a bit like I actually had an addiction." (P5)

The words used to describe MOH as an abuse caused ambivalent feelings and made some participants feel stigmatized by the health care professionals: "A good explanation of MOH is important in order to prevent a feeling of being substance addict" (P5). During the PEP, feelings of stigmatization was articulated and dealt with, so the participants could work constructively with their self-perception. In general, participation seemed to have contributed to a greater openness about the headache and, thus, had helped breakdown the taboo about feeling stigmatized. An informant said, "My boyfriend knew about my headaches, but not how bad it really was—now that I've told him more about it, he's a much better support for me. (. . .) The education has made me open about my situation. It's really positive." (P5)

Experience of Motivation for Behavior Change During Participation in the PEP

The participants reported different motivational incentives for participation in the PEP. Some of the most common reasons were "hope of cure," "generate tools to manage headache differently," "to increase quality of life," and "to gain increased knowledge about headache." Another motivational factor for participation was the need for support and

follow-up after withdrawal of the medication. Several participants found it challenging that they had to be actively engaged in the process and that their everyday lives were in focus during the PEP, "Sometimes I wished that I hadn't participated because I'm such an introvert person, but now I can see that it has been rewarding" (P2). Paradoxically, these challenges, along with the nurses' questions, were elements the participants also mentioned as reasons for gaining self-awareness and reflect and think differently: "I became really good at self-awareness and could suddenly see inexpedient things which I could reflect upon. To be more candid and put feelings into words changed something for me" (P6). The participants had not expected the PEP to be individually tailored, however, they all expressed that it worked well for them:

I was afraid that the teachers would "impose" something on to me, but then I realised that that wasn't the case (. . .). I was the one who sat the agenda and had to figure out the solutions. I liked that approach" (P3). Overall, the statements indicated that active involvement increased the participants' motivation to alter coping strategies and thereby to change behavior.

Discussion

Changing Coping Strategies After Participating in the PEP

Before entering the PEP, the participants used many resources to worry about when they would get the next headache attack and how to reduce the headache. The focus on pain reduction and prevention seemed to contribute to an overuse of medication. This finding is supported by another study, showing that repeated attempts to control the pain with medication may initiate an overuse of medication (34). Furthermore, an interview study has emphasized that medication was described by the MOH participants as being the only effective coping strategy and, therefore, it became indispensable to them (23). According to Lazarus, there are 3 types of coping strategies: (1) problem-focused coping, which includes seeking information/counselling, drawing on past experience, and focusing on problem solving; (2) emotion-focused coping which includes seeking social support and avoiding/daydreaming; 3, focused coping includes focus on basic values and beliefs/goals or positive thinking (31,35). A study showed that headache patients who primarily used problem-focused coping strategies more frequently developed MOH (34). In parallel to Lazarus' coping definitions, the change of behavior the participants shared may represent a coping process, facilitated through attending the PEP. Through exercises, conversations, and reflections, the participants seemed to change their perception of headache, which led to an increased self-awareness and acceptance of their headache. The headache thus seemed to get a less central role in their minds, as they focused on positive things in their everyday lives. These findings are consistent with previous studies, showing that acceptance of the headache was related to a more positive attitude in everyday life (19,20).

Self-Perception and Feeling of Stigmatization

In general, the participants' increased belief in their abilities to change behavior seemed to contribute positively to maintain the changed behavior. This can be interpreted as increased self-efficacy. The concept of self-efficacy addresses confidence in your own ability to organize and perform a specific task, behavioral changes, or solve a specific problem (36). The theory stresses that a person's experience of enhanced self-efficacy supports the behavioral change process. A systematic review found moderate evidence for low self-efficacy as a potential prognostic factor for poor treatment outcome among chronic headache participants (37).

Our findings demonstrated that some of the participants experienced ambivalent feelings about their ability to maintain a changed behavior. By exploring their ambivalence associated with behavioral changes by the use of MI, they considered both negative and positive aspects. Thus, the PEP seemed to enable the participants to choose alternative coping strategies to manage headache attacks than previously. In terms of defining themselves as addicts and feeling stigmatized, some participants were ambivalent. This self-image could be related to Goffman's term self-stigmatization, which refers to the reactions of people belonging to a stigmatized group. These people may reverse public stigmatization toward themselves, causing them to feel different (38). This raises the importance of health care professionals to use clear wording, explanations, and definitions of MOH during the PEP and in clinical settings, in order to eliminate the participants' feeling of being different and stigmatized.

Experience of Motivation for Behavior Change During Participation in the PEP

The individualized approach in the PEP seemed to increase the motivation for behavioral change, as the participants found it highly relevant to work with their everyday life problems and challenges. A recently published narrative review found that readiness for change, motivation, and self-efficacy were factors of importance to maximize adherence and, thereby, treatment outcome in patients with headache (39). It has been suggested that MI could be a suitable approach for headache treatment covering the above-mentioned elements (9). By exploring resources, values, and attitudes, participants can be stimulated to find their own inner motivation for behavioral change (40). This is in line with our findings, where the participants seemed to find the MI approach suitable, as this allowed them to be actively involved in the treatment and to focus on their specific challenges.

Our findings added useful knowledge about the importance of continuing support from health care professionals for the participants to maintain their decreased medication use. Additionally, our findings add to previous research which emphasizes the need to combine withdrawal of medication with education and /or behavioral treatment (4,7,9,12,41). Future studies could benefit from interviewing both participants who participated in an educational program and participants from the control group as this potentially would generate some additional interesting aspects on differences and effects from behavioral treatment.

Methodological Considerations

The main strength of this study is that, to our knowledge, it is the first to explore MOH patients' experiences from participating in a PEP focused on coping strategies and behavioral changes. The open approach in the individual interview where the interviewer tried to bracket own preunderstandings and the confident relation the interviewer established with the participants in the interviews seemed to allow the participants to share their experiences openly. However, the design with interviews performed on average 2 years after attending the PEP may have had implication for how detailed reflections and experiences the participants were able to remember.

Although we used convenience sampling, the participants varied with respect to age, years lived with headache, employment status, and educational setting in accordance with our aim for maximum variation. In addition, the distribution of gender among the participants reflects the distribution of gender in MOH patients in the Headache Clinic in general.

Based on the abovementioned limitations, our findings need to be interpreted in relation to the context in which the present interview study was conducted and may not necessarily be transferable to other patients' in other contexts.

Conclusion

Participation in the PEP seemed to lead to a feeling of increased self-efficacy and the ability to focus on new coping strategies and behavioral changes, such as shift of focus, and to use positive thinking. The participants' attention shifted from problem-focused coping to emotional and focused coping strategies as they accepted the headache as a decentralized part of their everyday lives. The communicative approach using MI thus seems suitable for the participants, as it allowed them to be actively involved in their own treatment. Experiences regarding feelings of stigmatization and ambivalent emotions related to a behavior change were essential among the participants.

Authors' Note

The data sets used and/or analyzed during the current study are available from the corresponding author on reasonable request. In accordance with the Declaration of Helsinki, both oral and written information was offered to the participants before written consent was obtained. The participants were informed that they could withdraw from the study at any time and that the interviews were confidential. In accordance with Danish law, the study was reported to the Danish Data Protection Agency (2008-58-0035 [ID 2638]) and was conducted and recorded in accordance with the criteria outlined in the COREQ statement.

Declaration of Conflicting Interests

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