

Chronic tension-type headache and coping strategies in adolescents.

A qualitative interview study

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Abstract

Objective

Headache is the most common cause of chronic pain in children and adolescents, and may influence on several of the life's arenas like high absence from school and inability to maintain leisure time activities. Adolescents with chronic headache also report co-morbidities such as anxiety, depression, insomnia and reduced quality of life. This study aimed to explore which strategies adolescents use to cope with chronic tension-type headache in everyday life.

Methods

A qualitative design with semi-structured individual interviews was used. A strategic sample of 17 adolescents aged 14 -19 with tension-type headache participated in the study. The interviews were audiotaped and transcribed verbatim. Transcripts were analyzed using systematic text condensation.

Results

To deal with the headache in everyday life, the adolescence expressed that it is important to have a good structure during the day, especially regarding regular meals and enough sleep. Sufficient rest and relaxation were also highlighted as crucial. Some of the adolescence had tried different therapies to help ease the pain, but with varying effect. All of the adolescents had used or were using pain relievers, but they were ambivalent to the benefits. Low-intensity physical activity were perceived as beneficial and gave increased overall well-being. Such activity also gave release and distraction from the headache.

Conclusion

The adolescents used both problem-focused active strategies and emotion-focused passive strategies to deal with their headache in daily life. Through exploration and awareness of the types of behaviour that worked and did not work, they had arrived at strategies that helped them cope with their headache and its consequences.

Key words

Adolescence, headache, coping, adaption, psychological

Introduction

Headaches are the most common cause of chronic pain in children and adolescents (Hockaday, 1991; King et al., 2011). The Nord-Trøndelag Health Study (HUNT) has shown that every third adolescent experiences recurrent headaches (Zwart, Dyb, Holmen, Stovner & Sand, 2004). Chronic headaches in adolescents can have consequences such as absence from school, inability to maintain social activities (Bruijn et al., 2009; Roth-Isigkeit, Thyen, Stöven, Schwartzenberger & Schmucker, 2005), additional disorders such as anxiety, depression, problems sleeping and reduced quality of life (Rabner, Kaczynski, Simons & LeBel, 2017; Blaaw et al., 2015; Bellini et al., 2013).

Living with chronic pain can be discomfoting and threatening and act as a stressor in everyday life (Boekaerts & Röder, 1999). Chronic pain is a multidimensional phenomenon involving both physical and psychosocial aspects that can be challenging to deal with (Gatchel, 1999). Coping strategies can help a person deal with external stressors by changing or accepting the situation or by gathering information to remedy the situation. Lazarus and Folkman (1984, p. 141) define coping as ‘constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person.’ They distinguish between problem-focused (active behaviour) and emotion-focused (passive) coping. Problem-focused coping involves efforts to reduce or lower (resolve) these demands and thereby change the source of stress. Emotion-focused coping is aimed at reducing emotional reactions in connection with stress and includes strategies such as seeking social support, withdrawal or social isolation (Compas et al., 2017). Both locus of control and self-efficacy are crucial factors in dealing with pain and difficult situations (Bandura, 1977; Rotter, 1954). Both concepts are central to cognitive perspective and represent important positive psychological factors in pain management and functioning in connection with general physical pain conditions and headaches (Stewart & Yuen, 2011; Kalapurakkel, Carpino, Lebel & Simons, 2015; Carpino, Segal, Logan, Lebel & Simons, 2014).

A systematic review has shown that children with recurrent headaches use different coping strategies (Bandell-Hoekstra, Abu-Saad, Passchier & Knipschild, 2000).

Passive coping strategies are most common, such as use of medication and lying down to rest. As children grow up, their ability to cope with headaches improves without having to rest or choosing lighter activities (King & Sharpley, 1990). Frare, Axia & Battistella (2002) found a positive link between adaptive routines in the family and the child's ability to cope. Adolescents with both chronic headaches and mental health problems more often use internal strategies such as keeping feelings inside, abusive substances and talking themselves out of problems compared to those without comorbid mental health problems (Hartberg, Clench-Aas, Raanaas & Lundqvist, 2015).

Qualitative studies addressing adolescents' experiences living with headache are scarce. However, Walter (2017) found that adolescents with different types of headache felt distressed, used medications, sleep and transcendence to deal with the headache. We have not been able to find any qualitative studies examining coping strategies of adolescents in dealing specifically with chronic tension-type headache (CTTH). The purpose of this study is therefore to explore such experiences.

Materials and methods

We conducted individual in-depth interviews with adolescents about their experience living with recurrent headaches and the strategies they use to deal with their condition. A semi-structured interview guide was used to ensure that key topics would be identified. Open-ended questions made it possible for the adolescents to talk openly about their experiences of living and dealing with chronic headaches in their daily lives (Malterud, 2017). The study has been approved by The Regional Committee for Medical Research Ethics: REK 2010/749.

A strategic selection of 17 adolescents (11 girls) aged 14–19 with CTTH classified according to the criteria of the International Headache Society (ICHD) were invited to participate in the study. Exclusion criteria were all other types of headaches. Participants were recruited from paediatric neurologists, physiotherapists and public health nurses in four southern Norwegian counties. Adolescents who met the inclusion criteria were asked to participate in the study by their health professional. A declaration of consent was signed by both the adolescents and their parents. LS contacted the parents to arrange a time and location for each interview, which took place at designated offices, at the premises of the attending physician/therapist, at school, or at the participants' home. The interviews were conducted by LS.

The respondents received advance notice of the topics to be discussed in the interview, which would last anywhere from 30 to 60 minutes. The interviews began with an open-ended question about the nature of the headache and the experience of living with headaches on a daily basis. The interview guide served as a guideline and aid to ensure that all the planned topics would be covered. The respondents' narratives were followed up by more in-depth questions. In the course of the interview, new topics emerged that were relevant to the issue. The interviews were recorded on audiotape and transcribed verbatim immediately following the interview. In order to protect the confidentiality of the respondents and other persons mentioned in the recordings, fictional names of persons, institutions and locations were substituted as early as the transcription stage. The transcribed interviews were stored on a dedicated password-protected PC without online access.

Analysis

The analysis was conducted by LS and LHM using systematic text condensation (STC). STC is a method for thematic cross-case analysis that consists of four analytical steps (Malterud, 2012). The first step involves reading all the material to gain an overall impression. After several readings, a number of preliminary themes began to emerge. In the second step, we identified preliminary code groups based on the initial themes, and 'meaning units' describing the adolescents' coping strategies were identified and coded. The third step involved the establishment of subgroups that represented important aspects of each code group, and condensing the content by devising an artificial quotation. Statements that served as a good illustration for each subgroup were identified. Finally, we recontextualised the data by synthesizing the condensates from each code group. In this way, the content of each code group was summarised, and concepts reflecting the main variation in the participants' coping strategies were identified. The knowledge gathered from each code group and subgroup was summarised, and a description of the content of each code group was produced. Quotations from the text were used as illustrations. Each subgroup was given its own heading. We used a stepwise approach in order to allow adjustment of the interview guide, conducting an initial analysis after the first four interviews. Finally, the results were evaluated against previous research data on the subject.

The analysis was supported by Folkman & Lazarus' theory of coping (1984). Inspired by this theory, the identified coping strategies were categorised as problem-focused or emotion-focused.

Results

Five main categories of active and emotional strategies emerged from the analyses: 1) Structure and routines in daily life, 2) Low-level activity and walking are best, 3) Rest, relaxation and withdrawal, 4) Therapy – expectations and disappointments, and 5) Thoughts on use of medication in connection with headaches.

Structure and routines in daily life

Regular routines in connection with meals and adequate sleep at night were described as helpful and preventive. At the same time, headaches could have a negative effect on appetite, making it difficult to maintain good eating routines. Adequate sleep at night was cited as the most important factor in relieving pain and fatigue during daytime. Therefore, several of the respondents were attempting to incorporate good sleep routines. If they slept a lot during the day, it was difficult to fall asleep at night. Planning ample time for breakfast and preparing for the day ahead were experienced to alleviate stress. In spite of this, some respondents experienced that the pain gradually came sneaking up on them in the course of the day. One boy expressed it as follows:

'I go to sleep early, and then I get up early ... maybe an hour before I leave. Maybe I'll take a shower, have breakfast and really take it easy ... no stress or anything. It helps.'

Low-level activity and walking are best

Most of the adolescents tried to stay active on days when their headache allowed it. Running on hard surfaces and activities that caused jolts to the head often made the headache worse. The same was true of high-pulse running workouts, such as running tests at school. Calm jogging or simple walking/hiking contributed to alleviating headaches in some cases. Such light activity served as a form of recreation or distraction from the headache and led to a general sense of well-being and relaxation. One girl reported that she experienced it as a form of therapy. Even if light activity did not always relieve the headache, it resulted in a positive physical sensation, provided more energy and helped improve mood. Another girl who regularly did strength and stretching exercises said it improved her neck and shoulder pain. One boy felt it was best to be out in nature and said the following:

'I get some peace of mind. I get a feeling of freedom and calm. We move at a good pace, make a stop and light a bonfire, grill something and chop wood – slightly depending on the season, but it's quite a lot of physical activity.'

Rest, relaxation and withdrawal

Many of the adolescents mentioned that lying down and taking a rest when they had a headache was important, especially after school. They used it as a kind of active respite from pain and stress. Many felt it improved their headaches and gave them a general sense of calm and relaxation. They found it helpful to disconnect from the outside world and get time off from external stimuli. Having the opportunity to be alone in a quiet room without sound, light or other disturbances was essential. A number of them preferred to lie down and read or listen to an audiobook, or simply lie stretched out calmly and think of something other than their headache. Some had experienced that their headache almost disappeared if they additionally got some sleep, while others experienced that it made things worse. One girl put it as follows:

'I think sleeping helps me the most. Because I need to unplug from what's going on around me. I just lie in my room or on the sofa – no sounds around me, just relaxing and closing my eyes and ... thinking a bit. I think it's great, because I know nothing's going to bother me. It's lying there at the same time, but I'm able to focus a little on something else instead of the headache.'

The adolescents stressed the importance of care and support from their parents in order to function well in their everyday lives, but they could not handle social interaction with others when their headache was acting out. If they were going to be together with friends, it was best to be in quiet surroundings with close friends who were familiar with their situation. Participation in larger gatherings with many people and noise could aggravate their headache and generally make them feel worse for several days afterwards. Therefore, their wish to participate had to be weighed against the subsequent drawbacks.

Therapy – expectations and disappointments

Many of the respondents had tried various traditional and alternative therapies, but did not feel that these initiatives had been of any particular help. Some of them recounted brief conversations about their headache with a physician or a nurse. Having tried different types of therapy without any results, a number of them had lost faith in receiving help from treatment. A 17-year-old boy described major disappointment and

resignation with therapists who raised his expectations of getting well after a few treatments, but did not experience any change himself. He described his experiences as follows:

'They didn't even touch me before telling me they had a solution. Once you've gone to so many for so many years, you become cynical. You lose hope. But I haven't lost it completely, you know. I haven't given up, but it's like you don't believe in any miracle cures anymore.'

A 17 year old girl described her feelings as follows:

'I went to a therapist once a week for a year. It felt good to have some immediate pain relief, but it didn't last. I still have a headache every day. I have trouble sleeping and never manage to relax. Somehow, you lose faith.'

Some continued to be hopeful of improvement despite having gone through lengthy treatment options, but they were unsure of what to choose in the future. None of the respondents mentioned that they had tried cognitive behavioural therapy (CBT).

Thoughts on use of medication in connection with headaches

All of the adolescents reported that they had used or were using pain relievers. Most of them, however, had found that medication did not help, and were also sceptical about their use. Some commented that they got nauseous, drowsy and tired when they took medication and had a general sense of discomfort in connection with this. The side effects could reduce their concentration at school and in recreational activities. Those who used medication did it mainly to improve their night sleep. Melatonin and various antidepressants were frequently mentioned. This did not necessarily improve the headache itself, but at least they got to sleep. One girl said:

'He gave me some tablets – something to calm me down. They helped, but you can get addicted. You're supposed to do well in sports, and those two things don't mesh. But it got me through the night.'

We discovered that some of the oldest respondents, who had lived with headaches for several years, had actively reflected on making changes in their daily lives. Our conversations revealed that in the course of the years, they had experienced and reflected on what affected their headaches positively and negatively. They were preoccupied with finding a kind of balance in several areas. This included a more

critical and correct use of medication, appropriate exercise and a more balanced approach to diet, rest and sleep. They also had an awareness of stressors and triggers in their daily lives. After having tried many different health professionals and types of therapy without any particular effect, they had eased up and put the project on ice for the moment.

Discussion

Typical problem-oriented strategies dealing with the structure and planning of everyday life and moderate physical activity, and more emotion-oriented strategies such as distraction, withdrawal and social isolation were used to deal with headaches in daily life. These strategies were used not only to minimise and control the headache and its consequences, but also to prevent new attacks. Several of the respondents said they were unable to find effective coping strategies and felt helpless when it came to dealing with their headaches. This is the first study interviewing adolescents with CTTH about their coping strategies. Especially the participants' identification of moderate physical activity as a coping strategy is a new contribution, and adds knowledge to this field.

Methodological considerations

We chose to collect information about how adolescents handle CTTH by conducting qualitative in-depth interviews. The safe setting of the interview allowed participants to freely reflect on their thoughts and experiences of living with chronic headaches and what they do to relieve the problem in their daily lives. The richness of information varied with each individual interview, but the 17 interviews yielded a great breadth of experiences in connection with how adolescents cope with recurrent headaches. The quality of the first interviews was somewhat low as they involved younger participants who were not as willing to share their experiences. Later interviews involved older respondents who provided more extensive information. Additionally, new aspects that shed light on the issue kept emerging during the interview process.

Both authors have broad clinical experience, including work with the patient group in question, and therefore had some prior knowledge of the coping strategies used by adolescents with recurrent headaches. Knowledge about the subject, as well as experience in interviewing young people, may have been an advantage during the interview process. This made it easier to ask relevant questions and follow up the conversations along the way. The disadvantage of knowing about the subject

beforehand is that the interviewer may unconsciously hold preconceived attitudes and assumptions. Examples of our preconceptions were strategies using medications and relaxation techniques. This may to some degree have hindered us in being open to new hypotheses. The use of medications was confirmed, but relaxation did not emerge as a topic in the interviews. We believe unconfirmed preconceptions to be a strength, indicating that the study reveals new knowledge.

The interviewer may have misinterpreted the respondents, thereby potentially impairing the validity of the data. This we attempted to avoid by validating the statements along the way. In addition, we performed an evaluation after the initial interviews and adjusted the interview guide to increase the quality of information and variation.

Our study focuses on individual coping strategies, not on the possible role of pressure from society. The expectation to perform well at school is described as one of the most important reasons for stress in adolescents (Klinger et al., 2015). School-related stress is an external stressor that may maintain and aggravate the headache, and efforts to reduce such stress may be helpful.

Discussion of the results

Structure in daily life, such as a good night's sleep, drinking enough fluids and eating healthy and regular meals were emphasised as helpful strategies in reducing headaches. Most important were good sleep routines. Milde-Busch et al. (2010) did not find any connection between skipping meals or insufficient fluid intake and headache in adolescents. However, Moschiano et al. (2012) found a clear association between headache and irregular intake of meals (especially breakfast) and sleep disturbances, with a worsening of headaches. There is good evidence that improved sleep routines have a positive effect on children and young people with migraines (Bruni, Galli & Guidetti, 1999). In addition, good family routines have been shown to affect both children's quality of life and their ability to cope with headaches (Frare et al., 2002).

Having control of the day's tasks was mentioned as an important factor in coping. This entailed avoiding stress, for example by allowing extra time in the morning, eating breakfast and being well-prepared for school. The participants had learned that calm physical activity was beneficial and allowed them to think of something else than their headache and daily demands. Calm physical activity was experienced as energising by providing fresh air and increasing the general sense of well-being. Hard

running workouts and other activities involving jolts to the head, however, were identified as factors in triggering headaches. This has also been found in earlier studies of adolescents with migraines (Sarioglu et al., 2003; Walter, 2017) and may suggest that the participants in our study had overlapping symptoms with migraine, something not uncommon among young people (Karli, Bican & Zarifoğlu, 2010; Krogh, Larsson & Lind, 2015). Moreover, adolescents with recurrent headaches often suffer from overwhelming pain, and this in itself contributes to preventing them from participation in both leisure activities and social gatherings (Aruda & Bigal, 2012; Walter, 2017). Adolescents with chronic pain may benefit from some form of customized adapted physical exercise. Moderate exercise can have a general modulating effect on chronic pain, contribute to lower stress levels, and improve depression-related symptoms (Kawi, 2016; Naugle, Fillingim & Riley, 2012).

Sitting down to rest and perhaps taking a short nap was a coping strategy used by most of the participants in our study, and is a finding supported by other studies (Helvig & Minick, 2013; Bandell-Hoekstra et al., 2000). This has been shown to be the most common and effective mastering strategy in adults with tension-type headaches and children with migraines (Ong, Stepanski & Gramling, 2009; Leiper, Elliot & Hannaford, 2006; Sarioglu et al., 2003). Use of sleep and ‘napping behaviours’ to relieve headaches can result in poor sleep hygiene and precipitate insomnia, or over time serve as a perpetuating factor for chronic insomnia (Ong et al., 2009).

All the adolescents in our study lived at home and were thus surrounded by caregivers who provided social support in several areas. When pain was at its worst, however, the participants did not want to talk to anyone, preferring to withdraw and be on their own. The tendency to withdraw from social settings and isolate oneself has also been observed in previous studies (Walter, 2017; Hartberg et al., 2015; Helvig & Minick, 2013). Adolescents may face the choice of either pressing on and enduring the pain or isolating themselves to seek relief (Helvig & Minick, 2013). By not exposing themselves to stress, strenuous workouts, hunger or social activity, they can prevent the headache from getting worse. Too little exposure and avoidance, on the other hand, can have adverse long-term effects and thereby function as maladaptive coping strategies (Carver & Connor-Smith, 2010; Zeidner & Saklofske, 1996). Therefore, it is important to find a good balance between avoidance and exposure in this regard. The consequences of avoiding activity and exercise can lead to physical

deconditioning, increased muscle pain and maintenance of chronic pain (Vlaeyen & Linton, 2000).

Nearly all the participants in our study had tried different forms of therapy. None of the adolescents had tried CBT, even though this has proved to be the most effective treatment for headache in children and adolescents (Fischer et al., 2014). This may suggest that physiotherapists and other health care workers ought to acquire more expertise in this area. Strength exercises and endurance training have also been shown to have a favourable effect on headaches and life quality in children and adolescents (Tornøe et al., 2016). This finding was confirmed by one of the participants in our study who reported that strength exercises helped against neck and shoulder pain.

The majority of participants had used simple analgesics to relieve their headaches, but without experiencing any particular improvement. This is in line with findings in other studies (King & Sharply, 1990). A number of participants found that the use of medication helped improve their sleep, a finding that is also supported by other studies (Gelfand & Goadsby, 2016; Miano et al., 2008). There are no clinical guidelines for drug use in children and adolescents with CTTH.

In Lazarus & Folkman's (1984) theory of stress and coping, coping is determined by cognitive evaluations and by the resources an individual uses to manage a situation. Emotion-focused coping tends to predominate when people feel that the stressor is something that must be endured, whereas problem-focused coping tends to predominate when people feel that something constructive can be done (Folkman & Lazarus, 1980). The adolescents in our study used both problem-focused (structure and planning of everyday life and moderate physical activity) and more emotion-focused strategies (distraction, withdrawal and social isolation). Taking advantage of medicines and various forms of therapy can be seen as a problem-focused strategy used by young people do something actively in hope of getting better. On the other hand, they can be seen as more passive strategies in the sense that this patient group relies on external forces (external locus of control; Bandura, 1977). The ability to shift between strategies, for example using both problem-solving and distraction to full advantage, becomes more advanced throughout adolescence and into early adulthood (Skinner & Simmer-Gembek, 2007).

The effects of any given coping strategy can be context-dependent. Lazarus and Folkman (1984) argue that there are no universal adaptive coping strategies that are suitable to all persons in all situations. There are arguments supporting both the

benefits of a rich repertoire of positive coping strategies (Litt & Tennen, 2015; Boekaerts & Röder, 1999; Rudolph, Dennig & Weisz, 1995), as well as use of a few good coping strategies (Worchel, Copeland & Barker, 1987). Our study showed that the adolescents used different self-initiated strategies, and that some responded well to certain strategies while some responded better to others. The oldest among the adolescents had more experiences with and reflections on what worked and what did not. Some adolescents felt that nothing helped and described a feeling of hopelessness regarding coping with their pain.

Conclusion: The adolescents in our study used both problem-focused active coping strategies and emotion-oriented strategies to deal with their headache in daily life. Through exploration and awareness of the types of behaviour that worked and did not work, they had arrived at strategies that helped them cope with their headache and its consequences. The oldest adolescents had gained experiences with a bearing on how they related to the use of medications, and had found an adaptive type of exercise that worked for them. They were also more structured in regard to diet, rest and sleep. Unable to find a treatment that helped, they had begun to concentrate on self-initiated behaviours and strategies. This requires both experience and a certain level of maturity. Some of them, especially the youngest participants, were still in a trial-and-error phase in which they felt their way forward and gathered experiences. Others believed their situation to be hopeless and continued to wait for a treatment that could help.

Implications for physiotherapy practice: The present study can contribute to a better understanding of how adolescents cope with long-term headaches in daily life. The results will be of use in meeting these patients in clinical practice and enable physiotherapist to provide qualified advice on coping strategies. The information that has emerged can contribute to a more comprehensive approach and more adapted treatment options for these patients. Additionally, the study represents a scientific contribution to the knowledge base with regard to understanding and helping adolescents who live with chronic pain. Schools and health personnel ought to implement initiatives early on to support and help this group of adolescents. Each adolescent should receive help in finding his or her own individual resources and together explore and advise on good coping strategies. CBT and psychological interventions have shown good effect in connection with anxiety, depression and CTTH. Therefore, they represent important treatment options in combination with

other viable measures such as motivational interviewing, reasonable use of medication and specific exercise, and should be included as part of the training for physiotherapists who treat these patients.

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