

STRIVING FOR CONTROL AND ACCEPTANCE TO FEEL WELL

- Experiences of living with migraine and attending physical therapy

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To my children

Sanna and Ida

Writing gives appearance and body to thought.

And as it does, we disembody what in another sense we already embody.

However, not until we had written this down did we quite know what we knew.

Van Manen 1997 p.127

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ABSTRACT

The overall aim of this doctoral thesis was to describe and develop an understanding of persons' experiences of living with migraine and managing their lives to feel well, and to elucidate their experiences of physical therapy. Qualitative, narrative interviews (I-IV) were conducted with individuals to explore and describe their experiences of living with migraine. The persons with migraine were asked to draw a picture of their experiences to support their narration and the interview continued after the drawing was complete (II, III). To interpret the meaning of living with migraine, the transcribed text was analyzed using a hermeneutical-phenomenological approach (I, II, IV), and the interviews were analyzed using qualitative content analysis (IV) to describe the experiences of acupuncture.

The findings show that living with migraine meant living with the uncertainty about having an attack and striving to control the migraines (I, II, IV). To increase their sense of control, the persons with migraine tried to identify and manage their migraine triggers and they tried to find effective ways of alleviating the attacks (I, II). They also attempted to amplify the good things in life, which increased both their sense of control and their well-being (II). Living with migraine meant living with the fear of being misunderstood and doubted. When persons with migraine made peace with being afflicted, they received an inner sense of security from which they could view more possibilities than limitations in life (I, II). When the person with migraine attended physical therapy, they invested their time and energy towards feeling well, and it was important that the intervention rewarded their effort with increased health. The interaction with the physical therapist was an important aspect of physical therapy. The persons with migraine emphasized the need to be trusted and to receive individual attention, and they also wanted to feel confident in their physical therapist (III, IV).

In conclusion, knowledge about the meaning of living with migraine is important for physical therapists and other healthcare professionals who encounter persons with migraine. By listening to persons' experiences of migraine, their ability to control their migraine, their acceptance of their migraine and their general sense of well-being, new possibilities for individually adapted interventions and empowering actions can be revealed. In addition, physical therapists should consider the need for trust and confidence as important aspects of treating persons with migraine to improve their practice.

Key words: experiences, headache, health, migraine, physiotherapy, well-being.

LIST OF ORIGINAL PAPERS

This doctoral thesis is based on the following papers, which will be referred to throughout the text by their Roman numerals:

- I. Rutberg, S. & Öhrling, K. (2012). Migraine – more than a headache: Women’s experiences of living with migraine. *Disability and Rehabilitation*, 34(4), 329-336. DOI: 10.3109/09638288.2011.607211
- II. Rutberg, S., Öhrling, K. & Kostenius, C. (2013) Traveling along a road with obstacles: Experiences of managing life to feel well when living with migraine. *International journal of qualitative studies on health and wellbeing*. <http://dx.doi.org/10.3402/qhw.v8i0.19900>
- III. Rutberg, S., Kostenius, C. & Öhrling, K. (2013) Professional tools and a personal touch: Experiences of physical therapy of persons with migraine. *Disability and Rehabilitation*. DOI:10.3109/09638288.2012.748838
- IV. Rutberg, S. & Öhrling, K. (2009) Experiences of acupuncture among women with migraine. *Advances in Physiotherapy*, 11, 130-6. DOI:10.1080/14038190802242053

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INTRODUCTION

The focus of this thesis is to explore persons' experiences of living with migraine and their experiences of physical therapy. Based on the existing field of research and my experience as a clinical physical therapist, my belief is that physical therapists' knowledge and understanding about what it means to live with and manage a certain disorder, such as migraine, could impact the interaction with the person and the outcome of physical therapy. I further believe that the interactions between the physical therapist and the patient and the patients' experiences of the intervention are intertwined and affect each other. By using a qualitative approach in this thesis, it is possible to achieve rich descriptions of the participants' experiences as a foundation on which to build an increased understanding of the phenomenon under study. Furthermore, by turning to the lived experiences of persons with migraine, it is possible to understand what it is like to be in the world as a person living with and managing migraine. The data in this thesis were collected through in-depth individual interviews using a narrative approach. In two of the studies the participants made drawings of their experiences to facilitate their narratives in the interviews. Two methods were used to analyze the data; 1) hermeneutic-phenomenology, which was used to explore the way in which persons with migraine may experience being in the world, manage life to feel well and experience attending physical therapy, and 2) qualitative content analysis, which was used to describe the experiences of acupuncture in a structured way.

BACKGROUND

Perspectives on physical therapy

Health is the foundation of physical therapy, both as a profession and as science. As a profession, physical therapy aims to prevent impairment and promote health by maximizing movement and functional ability throughout the lifespan; it encompasses physical, psychological, emotional and social well-being. The physical therapy profession is guided by the physical therapy process (World Confederation for Physical Therapy, 2011). The central assumptions that characterize physical therapy are that movement is an essential element of health and well-being, that individuals have the capacity to change, that the interactions between the physical therapist and the patient are an integral part of the physical therapy process, and that the diagnosis and the patient's goals guide the physical therapist in determining the prognosis and the most appropriate intervention strategies (Broberg & Thyni-Lenné, 2010; World Confederation for Physical Therapy, 2011).

During rehabilitation, including physical therapy, there is a focus on evidence-based practice, which aims to help practitioners make the best decisions about their patients (Dijkers et al., 2012; Goldstein et al., 2011). According to Carter, Lubinsky and Domholdt (2011), there are three equally important aspects of evidence-based practice; the best research evidence, clinical expertise and patient values. Even though both clinical expertise and patient values must include aspects of interaction, the interaction is rarely mentioned in evidence-based practice. The importance of the interaction between the physical therapist and the patient has been stressed (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010) and the specific effects versus the general effects of a physical therapy intervention have been discussed (Miciak, Gross, & Joyce, 2011).

Common factors, such as therapist qualities, relationship elements and client characteristics, most likely affect the outcome of physical therapy in the same way that they affect outcomes in psychotherapy, according to Miciak et al. (2011). These common factors explain as much as 70% of the outcomes of psychotherapy treatment, whereas only 8% was attributable to the specific effect of a certain intervention (ibid). In addition, Moyer, Rounds and Hannum (2004) concluded that common factors, especially interpersonal contact, interpersonal communication, the recipient's attitude about therapy and the therapist's characteristics, could explain more of the outcome in massage therapy than existing theories, such as gate-control and promoted parasympathetic response.

Some studies suggest that the patient-therapist relationship affects the outcome of physical rehabilitation (Hall et al., 2010; Klaber Moffett & Richardson, 1997). In addition, the physical therapist's sensitivity and ability to negotiate common ground is also thought to affect outcomes (Oien, Steihaug, Iversen, & Råheim, 2011). According to Potter, Gordon and Hamer (2003b), it is important for physical therapists to be aware of their part in the intervention and the interaction with the patient, and they concluded that more research was needed, especially from the patient perspective. In addition, Tickle-Degnen (2002) emphasized the importance of further understanding the interaction between clients and therapists to shape evidence-based practice in rehabilitation.

Health perspectives

According to Broberg and Tyni-Lenné (2010), in the field of physical therapy, health is not only the absence of disease; it is also the possibility to reach one's goals in life. This definition of health was built upon the World Health Organization's [WHO] (1946) definition of health as a state of complete

physical, psychological and social well-being and not merely the absence of disease or infirmity. The concept of health has been debated, and the WHO definition has been questioned because it is too vague, has limited practical use and is partially composed of non-definable terms (Emson, 1987; Saracci, 1997). Saracci (1997) concludes that “a state of complete physical, psychological and social well-being” corresponds more to happiness than to health, implying several consequences for the society whose task is to provide health among their citizens. Instead, Saracci suggests that the definition of health should be “a condition of well-being free of disease or infirmity and a basic and universal human right” (1997 p.1410). Even though this definition may make it easier to define health, it does not allow a person to be healthy if he or she is afflicted with a disease or a disorder like migraine. Instead, Bircher (2005) has proposed the following definition: “Health is a dynamic state of well-being characterized by physical, mental and social potential that satisfies the demands of a life commensurate with age, culture and personal responsibility” (p. 336). This definition of health adds to the WHO definition that well-being is a dynamic state and that health is connected to different aspects of a person’s potential and the ability to satisfy the demands of life.

These definitions of health refer to well-being, but currently, there is no generally accepted definition of well-being. Instead, this term is often used synonymously with good health (Svensson & Hallberg, 2011). According to Lehnert, Sudeck and Conzelmann (2012), subjective well-being can be divided into different dimensions: psychological well-being, including both cognitive and affective; somatic well-being, including both physical self-evaluation and physical functioning; and social well-being. Although this conceptualization can be helpful on certain occasions, my view of well-being is in accordance with Sarvimäki (2006), who states that the concept of well-being rests on an implicit

view of what it means to be a whole and healthy human being. Therefore, while searching for answers about how persons with migraine manage their lives, it seems appropriate to avoid dividing well-being into different dimensions and instead view well-being as a sense of wholeness.

Living and managing life with migraine

Living life with migraine imposes a significant disability (Leonardi, Raggi, Ajovalasit, Bussone, & D'Amico, 2010), and migraine can impair quality of life (Brandes, 2008). In addition, migraine has been listed among the top twenty causes of disability (World Health Organization, 2001). Even though migraine attacks are recurrent and resolve rapidly, the effects of migraine are not limited to the periods during the attacks. According to Freitag (2007), living with migraine involves treating the current attack and worrying about the next one; thus migraines can produce an ongoing cycle of suffering.

In the Western world, approximately 15-18 % of women and 6-9 % of men are afflicted by migraine (Dahlof & Linde, 2001; Lampl, Buzath, Baumhackl, & Klingler, 2003; Lipton et al., 2007). Migraine is a chronic neurological disorder and currently has no cure. Migraines are usually divided into two sub-types, migraines without aura and migraines with aura (Headache Classification Committee of the International Headache Society, 2005). Typical characteristics of a migraine attack, which usually lasts between 4 to 72 hours, are a unilateral headache with a pulsating quality, moderate to severe intensity, nausea, photophobia, phonophobia and aggravation from physical activity. Persons suffering from migraines with aura also experience attacks of reversible focal neurological symptoms that precede or accompany the headache. The aura is typically connected to visual and/or sensory and/or speech symptoms that last

between 5 and 60 minutes (Headache Classification Committee of the International Headache Society, 2005). Even though these clinical characteristics are valuable in diagnosing migraine, they have limited value in describing what it means to experience a migraine attack. As far as I know, there is no research describing the meaning of an attack.

In the periods between attacks, it is common for persons with migraine to worry, and in some cases, they experience fear and anxiety in anticipation of the next attack (Wacogne, Lacoste, Guilibert, Hugues, & Le Jeune, 2003). When living with migraine, one obstacle is not knowing when the next attack is going to appear. The predictability of a migraine attack is low; only one out of five people with migraine were able to predict an attack within three days (Hu et al., 2010). The unpredictability of the attacks imposes a state of uncertainty in life that impacts the person's ability to make plans and engage in activities (Blumenfeld et al., 2011; Dowson & Jagger, 1999; Hu et al., 2010). Not knowing when the attacks are coming affects the person's sense of control, and according to Dowson and Jagger (1999) one third of persons with migraine believe that their problem controls their lives. The sense of lacking control also appeared in a study by Belam et al. (2005), who used the metaphor "handling the beast" (p. 89), to describe the participants' feelings about struggling with migraine. To increase their sense of security, persons with migraine organize their lives to avoid triggering a migraine, and Meyer (2002) found that women were constantly watching for signs of a migraine.

The impact of migraine extends to family, work and social relationships. Dueland, Leira, Burke, Hillyer and Bolge (2004) and Lipton, Stewart, Diamond, Diamond and Reed (2001) report that persons with migraine are unable to function fully at work during a migraine attack and that about half of the participants in the studies had missed work because of migraine in recent

months. Lipton et al. (2003) reported that almost half of the persons included in the study had missed family, social and leisure activities because of migraines in the last three months. In addition, Ruiz de Velasco, Gonzalez, Etxeberria and Garcia-Monco (2003) found that living with migraine negatively influenced quality of life and that the family environment and psychological well-being were most severely affected. Cottrell et al. (2002) reported that the effects on family members especially children, were troublesome. Suffering from a disorder that so clearly impacts aspects of social functioning and also affects persons in the person's with migraine immediate surroundings increases the burden of living with migraine and has the potential to increase feelings of guilt about being afflicted.

The impact on family, work and social relationships, however, is not a 'one-way street.' Persons with migraine are affected by the attitudes toward migraine among persons in their surroundings. Cottrell et al. (2002) stated that one burdensome aspect of living with migraine was feeling misunderstood by others. In addition, Moloney, Strickland, DeRosett, Melby and Dietrich (2006) discussed how women with migraine had feelings of guilt because of the stigma that migraine could be avoided if the women exerted sufficient self-discipline. Because being understood is central to feeling well with other chronic diseases, such as multiple sclerosis (Olsson, Skär, & Söderberg, 2010), it is important to determine whether this aspect appears when exploring the meaning of living with migraine and managing life to feel well. Peters, Abu-Saad, Vydelingum, Dowson and Murphy (2005) and Moloney et al. (2006) claim that more qualitative research is needed to help healthcare providers develop a deeper understanding of their patients' experiences. Understanding the meaning of living with chronic illness can help healthcare professionals make sense of

illness and view healthcare in a new way, which may increase the possibility that they will provide relevant and useful healthcare (Thorne, 1999).

Previous research on how persons manage their lives with migraine has mostly focused on how to control and abort their migraines, which has produced important insights into preventive actions. Persons with migraine actively manage their illness in highly individualized ways (Peters, Abu-Saad, Vydelingum, Dowson, & Murphy, 2003). To prevent migraine attacks, Varkey, Linde and Henoeh (2012) found that person alternated between avoiding migraine triggers and using migraine-inhibiting strategies, such as eating nutritious food, engaging in physical therapy or performing enjoyable activities to increase well-being. The authors also stated that balancing migraine prevention requires finding a middle course between letting migraine influence one's life completely and not letting it influence one's life at all, because those extremities both increase the risk of feeling controlled by migraine. According to Peters, Abu-Saad, Vydelingum, Dowson and Murphy (2004), people with migraine overwhelmingly engage in problem-solving actions to prevent their migraines, and the majority use prescription drugs to treat their migraines. In addition, Peters et al. (2003) tried to elucidate the decision-making process and found that people with migraine operated on the basis of a justification and consequence system for both acute and preventive management of migraine. Excluding the study by Varkey et al. (2012), which reported findings about introducing migraine-inhibiting strategies, I have not found any other studies that show how persons with migraine manage their lives to feel well beyond averting and handling the attacks.

Treating persons with migraine

Different countries have different guidelines about the treatments offered to persons with migraine, and Antonaci, Dumitrache, De Cillis and Allena (2010) found that the primary recommendation was the use of medications, even though non-drug alternatives are commonly recommended. However, the use of medication is complex, because pharmaceuticals vary in their side effects (Edmeads, 2006). Furthermore, persons may have medical contraindications or demonstrate little or no response to pharmacological treatment (Campbell, Penzien, & Wall, 2010). In addition, overuse of medication is a strong risk factor for migraine to develop into chronic daily headaches (Bigal, Rapoport, Sheftell, Tepper, & Lipton, 2004). Non-pharmacological treatments, many provided by physical therapists, play a growing role in the multidisciplinary management of headache disorders because the evidence supporting these therapies is increasing and because they can provide a greater sense of self-efficacy for patients (Sun-Edelstein & Mauskop, 2011). Among non-drug interventions, acupuncture is at least as effective as preventive medication (Linde et al., 2009) and bio-behavioral treatments (i.e., biofeedback, relaxation training and stress management) are effective treatments options for migraine (Buse, Rupnow, & Lipton, 2009; Sun-Edelstein & Mauskop, 2011). Cognitive behavioral therapy was effective in preventing migraine compared with a control intervention (Campbell et al., 2010) and Sun-Edelstein and Mauskop (2011) reported that it can be especially effective when the patient has a low level of self-efficacy and an external locus of control. Exercise has also been suggested as an intervention to decrease the number of attacks (Varkey, Cider, Carlsson & Linde, 2011). Even though these interventions are effective and safe, and acupuncture is considered relatively safe (Birch, Hesselink, Jonkman, Hekker, & Bos, 2004) they have the disadvantage of being time-consuming. Physical

therapy offers many of the recommended non-drug treatments for migraine, and a review has shown that a combination of exercise, relaxation and other physical therapy interventions was most beneficial for treating migraine (Biondi, 2005).

Among the physical therapy interventions provided to persons with migraine, acupuncture treatment has received much attention (Sun-Edelstein & Mauskop, 2011). There is increasing support for acupuncture as a treatment for migraine, even though there is no evidence that “true” acupuncture is more effective than “sham” acupuncture. Linde et al. (2009) concluded that acupuncture could be an alternative for persons with migraine who are willing to undergo the treatment. Griffith and Taylor (2005) and Paterson and Britten (2004) have produced the only studies I have found that describe the experience of undergoing acupuncture treatment; therefore, it would be interesting to further illuminate the experience of undergoing acupuncture treatment to increase the quality of healthcare.

Most studies investigating the effect of acupuncture on migraine tend to evaluate the number of attacks and their intensity (Linde et al., 2009) but there may be other valuable experiences worth investigating. Paterson and Britten (2003) found that individuals with chronic diseases, (including persons with migraine), who received acupuncture treatment reported more energy and positive changes in personal and social identity. Paterson and Britten (2003) further emphasized the importance of exploring the full range of outcomes from acupuncture treatment.

The interactions between migraine patients and healthcare professionals were emphasized by both Brandes (2008) and Edmeads (2006), who claimed that effective patient-therapist communication is a key factor in migraine prevention. In addition, the US Headache Consortium stated that it is crucial to

involve the migraine patient in the development of a management plan not only to succeed with the plan but also to empower the patient (Campbell et al., 2010). According to Buse et al. (2009), an increased understanding of migraine among healthcare professionals and communication about the burden of migraine with the patient can improve care. In addition, Ramsey (2008) argues that when women with migraine are recognized as truly suffering, some relief can be provided. However, some studies (Belam et al., 2005; Cottrell et al., 2002; Moloney et al., 2006) have shown that persons with migraine describe experiences when they were not taken seriously by healthcare personnel. These reports indicate the importance of exploring persons' with migraine experiences of their disorder and their experiences of healthcare. Moreover, to support practitioners and to improve future care and education, Anand and Sharma (2007) argue that more qualitative research is needed about managing migraine from the individuals' perspective.

RATIONALE

From the physical therapy perspective, an individual's health is perceived as a physical, mental, social and existential wholeness. Physical therapy aims to prevent impairment, promote health and alleviate and cure diseases and injuries to obtain or maintain optimal functional ability. To reach this goal when meeting a person with migraine, the physical therapist needs to use both the interaction with the patient and engage him or her in a physical therapy intervention. Even though the World Confederation of Physical Therapy has stated that the interaction between the physical therapist and the patient is an integral part of the physical therapy process, few studies address this aspect of physical therapy, and none that take the perspective of persons with migraine. In the evaluations of acupuncture treatment for migraine, migraine frequency, intensity and duration have been the dominant parameters. Exploring the experiences of physical therapy, including acupuncture, will reveal more factors that are important for the person with migraine, both during and after treatment. One aim in this thesis is therefore to explore and describe person's with migraine experiences of physical therapy.

Previous research has indicated that increased understanding of migraine among healthcare professionals can improve the care of these patients and that effective patient-therapist communication is a key factor in migraine prevention. Migraine is associated with significant disability, which affects well-being. However, only a few studies have captured the voices of persons with migraine and explored their life-world. Although some of the previous research describing life with migraine captures the meaning of being afflicted by migraine, there is still a need for more knowledge about how it feels to be a person living with migraine. Further, the research about how to manage life with migraine has mainly focused on strategies for preventing and managing migraine attacks. Studies that focus on health-promoting aspects of living with migraine are limited. By using a life-world perspective, it is possible to explore the meaning of living with migraine.

THE AIMS

The overall aim of this thesis was to describe and develop an understanding of persons' experiences of living with migraine and managing life to feel well, and to elucidate their experiences of physical therapy.

The specific aims were:

- to explore the meaning of living with migraine (I)
- to explore the lived experiences of managing life to feel well while living with migraine (II)
- to explore the lived experience of physical therapy of persons with migraine (III)
- to describe the experiences of acupuncture treatment among women with migraine (IV)

METHODOLOGICAL FRAMEWORK

Qualitative methods provide an opportunity to create rich descriptions, enhance understanding of a phenomenon and capture the voices of people who are rarely heard (Sofaer, 1999). Thus, qualitative approaches to headache research have the potential to improve healthcare professionals' understanding of headache disorders and to provide important insight into the perspectives and behaviors of persons with headache (Peters, Abu-Saad, Vydelingum, & Murphy, 2002).

Phenomenology and the life-world approach

Three of the papers (I, II, III) in the thesis used a life-world approach, which was chosen to gain a deeper understanding of what it means to live with migraine and manage life to feel well and to explore the lived experience of physical therapy among persons with migraine. Hermeneutical-phenomenology was chosen because it may yield findings that could potentially increase thoughtfulness and encourage people to act with more tact towards others (van Manen, 1997). To gain a deeper understanding of a phenomenon, the researcher needs to approach individuals who have experiences of the phenomenon to explore it in all its variations (Husserl, 1970). Therefore, it was necessary to approach individuals who live with migraine and listen to their experiences of the phenomenon as it occurred in their daily lives (i.e., their lived experiences).

Phenomenological research begins in the life-world, and van Manen (1997) argues that hermeneutical-phenomenological research entails searching for the meaning of lived experiences and of being in the life-world. The concept of the life-world was developed by Husserl as a foundation for scientific knowledge; we are all part of the world and participate in it. Therefore, the life-world is a personal world, and it is not possible to leave it. It is lived here and

now, but it carries history in memories and earlier experiences and also has a perspective on the future in hopes and expectations. The lived experiences of the life-world are our immediate experiences in the world, rather than our conceptualizations, categorizations or reflections on those experiences (Husserl, 1970). In developing the theory of the life-world, Husserl began with the “natural attitude,” his term for the approach we take to life that does not include analysis of things we do or situations we encounter.

Heidegger was the first to combine Husserl’s phenomenology with hermeneutics. He claims that to understand the meaning of a phenomenon, we must interpret experiences; thus, he drew attention to the being of beings (Heidegger, 1978). Van Manen (1997) built on Heidegger’s epistemology when he argued that phenomenology aims to understand the meaning of our lived experiences and, our being in the life-world. He further claims that hermeneutic-phenomenology is both descriptive and interpretive. It is descriptive because it requires one to be attentive to how things appear. It is interpretive because the “facts” of lived experiences are given meaning as they are experienced, and one needs to use words to describe a phenomenon, which is inevitably an interpretive process. In this thesis, I have tried to describe the phenomenon, but these descriptions are built on my interpretations and the interpretations of my co-writers of the meaning of their lived experiences.

Although, it would be incorrect to claim that one had reached a complete understanding of a phenomenon, it is important to strive for giving the experiences of the participants as much justice as possible. Husserl (1970) argued that studying the life-world in an unprejudiced way requires that we bracket our presumptions and pre-understanding, something he calls *epoché*. However, I side with the *epoché* critics and agree with Gadamer (1994) that no understanding is possible without pre-understanding and that it is not possible to place oneself outside the life-world when studying the meaning of lived

experiences. To understand a phenomenon that is built on lived experiences, the researchers must enter the hermeneutical circle: trying to remain open to the phenomenon to be able to understand more and more about it. Striving to capture the phenomenon appropriately has epistemological consequences, and Gadamer (1994) claims that we should expect that there is absolute meaning and should be open to all aspects of the meaning of the phenomenon. Furthermore, to attempt to remain open to the phenomenon as much as possible, my co-authors and I have been very attentive to our pre-understanding and presumptions.

The qualitative content analysis approach

Qualitative content analysis is not known to have any philosophical underpinnings. However, individual researchers have their own ontology and epistemology, which may impact their studies. Because the aim of study IV was to describe the experiences of acupuncture among women with migraine, a qualitative content analysis was conducted. The choice of method was based on the work of Krippendorff (2003) who claims that studies using content analysis can improve knowledge and offer practical guidance for action. According to Elo and Kyngäs (2008), content analysis produces a broad and condensed description of a phenomenon, yielding study findings that attempt to build a model of knowledge and show the interconnections between findings.

My horizon of understanding

Placing ourselves, the researchers, in the life-world has epistemological consequences, and according to Drew (2001), the researchers are creative co-contributors in understanding phenomena together with the participants.

Therefore, the phenomenon described and interpreted in a phenomenological study derives from the participants' lived experiences combined with the researcher's consciousness of the empirical world (Drew, 2004). Gadamer (1994) discussed the influence of the history of understanding and claims that presumptions derive from our traditions and that our interpretations emanate from the traditions in our horizon of understanding. In other words, the researcher's questions and ways of viewing a phenomenon are products of the way they project themselves. I further agree with van Manens (1997) and Drews (2001) perspective that it is essential to be aware of one's beliefs when performing phenomenological research. This awareness makes it possible to examine and question one's pre-understanding and remain open to more ways of understanding the participants' experiences.

Taking the perspective that the researchers are creative co-contributors to understanding a phenomenon also has consequences for the quality of a phenomenological study. According to Drew (2004), the value of the constructed truth of a phenomenological study depends on how rigorously and effectively the researcher's subjective experience of the phenomenon is explained and recognized as a contributor to the phenomenon. Furthermore, Drew (2001) states that self-awareness is the foundation of objectivity in phenomenological research.

My own pre-understanding and presumptions are partially related to my work as a physical therapist in primary care for 15 years, where I have met and treated persons with migraine. Neither I nor anyone in my immediate surroundings is afflicted by migraine or any other chronic disorder, which naturally influences my horizon of understanding. Moreover, I have worked as a teacher in the physical therapy department for 10 years, and in this role, I have reflected on the theories and assumptions, we hold within the profession.

METHODS

Design

This thesis includes four studies that use different qualitative methods for data collection and analysis. In studies I, II and III a qualitative research design with a hermeneutical-phenomenological approach was used. In study IV the qualitative data were analyzed using content analysis.

Participants and procedure

In this thesis, it was crucial that the persons participating in the studies had experiences of the phenomenon under study. That the participants varied in age, gender and background was not considered equally important (cf. Norlyk & Harder, 2010). In all four studies included in this thesis, the participants were purposefully sampled, guided by the following criteria: being at least 18 years old, having a diagnosis of migraine and speaking Swedish. Additional criteria for inclusion or exclusion are presented below in studies III and IV. All of the persons who volunteered to participate and fulfilled the inclusion criteria participated in the studies. The aim was to include both men and women in all four studies, but in studies I and IV, only women participated.

Physical therapists often use the terms ‘patient’ or ‘client’, when referring to the individuals in their care. A patient is defined as a person receiving or waiting for medical care, and the word is connected to the Latin word ‘pati,’ which means ‘to suffer’ (Deber, Kraetschmer, Urowitz, & Sharpe, 2005). The term ‘client’ carries connotations of a business relationship in which a person in need purchases professional services from another person (Deber et al., 2005). In this thesis, I have chosen to use the phrases ‘person with migraine’ and

‘individual with migraine’ to avoid labelling the participants in the ways mentioned above. An overview of the participants, recruitment procedures and data collection is presented in Table 1.

Table 1: Overview of the study participants, recruitment strategies and methods of data collection.

Study	Participants	History of symptoms of migraine	Recruitment method	Data collection
I	10 women with migraine	They had experienced symptoms for 10-45 years.	Swedish Migraine Association	Interviews and drawings
II	17 women and 2 men with migraine	17 had experienced symptoms for 9-59 years; 2 had experienced symptoms for approximately 1 year.	Swedish Migraine Association and physical therapist	Interviews
III	9 women and 2 men with migraine	9 of them had experienced symptoms for 9-59 years; 2 had experienced symptoms for approximately 1 year.	Physical therapist	Interviews and drawings
IV	10 women with migraine	8 had experienced symptoms for 10-34 years; 2 had experienced symptoms for 1-2.5 years	Physical therapist	Interviews

Study I

Ten women diagnosed with migraine participated in study I. The Swedish Migraine Association was contacted, and they agreed to forward letters to all members in northern Sweden. Eleven women and one man answered and were interested in participating in the study. Two persons were excluded; one had recently moved to southern Sweden, and the second person had not been diagnosed with migraine.

The women's ages ranged from 37-69 years, and they had experienced symptoms of migraine for 10-45 years. The number of attacks varied: 1-2 attacks per year for two women, 1-4 attacks per month for six women and 10-20 attacks per month for two women. They estimated the impact migraine had on their lives on a three grade scale: slight, medium or severe. Of the women, four classified the impact as medium, and six classified it as severe.

Study II

Nineteen persons diagnosed with migraine participated in study II. Two of these individuals also participated in study I. Eleven participants were attending physical therapy, and these persons were recruited by their physical therapists, who agreed to hand out information about study II and study III. Eight additional participants were recruited by the Swedish Migraine Association, which agreed to forward information about the study to members in northern Sweden.

The participants comprised 17 women and two men aged between 20 and 69 years; 17 persons had had their diagnosis for 9-59 years, and two persons had had their diagnosis for approximately one year or less. The number of attacks varied: 1-8 attacks per year for three persons, 1-4 attacks per month for ten persons, 5-8 attacks per month for four persons and 12-25 attacks per month for two persons.

Study III

Eleven persons diagnosed with migraine and attending physical therapy participated in study III. (They also participated in study II.) They were recruited

by their physical therapists, who agreed to hand out information about the study. To be included the participants had to be receiving physical therapy from a physical therapist for their migraine in addition to the criteria mentioned.

The participants comprised nine women and two men aged between 20-69 years. Nine of them had had their diagnosis for 9-59 years, and two of them had had their diagnosis for approximately one year or less. Four of them were attending their first period of physical therapy, and two were attending their second period. Five persons had been attending physical therapy for various periods over the past 3-20 years.

Study IV

Ten women who received acupuncture treatment for their migraine participated in the study. These women were recruited by their physical therapist, who agreed to hand out information about the study. To be included, the participants had to have received at least eight acupuncture treatments for migraine in an ongoing treatment series, in addition to the study criteria mentioned above. The criteria for exclusion were receiving other treatments from a physical therapist at the same time as they received acupuncture and having severe mental illness.

The women's ages ranged from 31-60 years, and they had had their symptoms for 1-34 years. Their current acupuncture treatment period varied from 2-24 months. The number of previous acupuncture treatment sets varied from two to nine sets. Three women were being treated with acupuncture for the first time.

Data collection

Qualitative research interviews were used to collect data in all of the studies included in this thesis. A qualitative research interview is a conversation that is characterized by its focus on the dynamic interaction between the interviewer and the interviewee, and special attention is placed on what is said (Kvale & Torhell, 1997). The interviews in this thesis used a narrative approach; the interview centered on a topic, and the interviewer encouraged the interviewee to describe his or her experiences of the topic with as few interruptions as possible. The use of narrative interviews is appropriate when the research aims to explore and understand experiences from individuals' perspectives (Bates, 2004). All of the studies in this thesis were guided by one or two broad questions, even though it is easy to lose sight of the fundamental research question during the interview because there is very little guidance offered in a broad question (van Manen, 1997). However, a broad question was used because it was important to avoid leading the person's story in any particular direction. A narrative interview requires attentive listening and explicit encouragement to facilitate the telling of the story, in the form of non-verbal or paralinguistic support and the demonstration of interest (Jovchelovitch & Bauer, 2000). As the interviewer, I paid particular attention to these facilitation skills, and when the interviewee came to the end of his or her story, I continued asking questions about events he or she had mentioned or about the topics of the research study to further explore the story (cf. Jovchelovitch & Bauer, 2000). In hermeneutical-phenomenology, the interview is used as a means for exploring and gathering narrative material, and according to van Manen (1997), it is essential for the interviewee to stay close to his or her experiences as they were lived.

To enable the participants to further narrate their lived experience, they were asked to draw their experiences in studies II and III. Paintings can give

shape to lived experiences, and they have been used in phenomenological research (van Manen, 1997). Leitch (2006) stated that by including the creation of images in research, it is possible to extend beyond the limits of language to capture the meaning of lived experiences in a holistic way. According to Guillemin (2004), using drawings as a complementary strategy for data collection has the potential to expand the researchers' interpretations of the many ways in which illness can be understood and experienced.

The interviews, which were tape-recorded, started with background questions, and the participants were asked to briefly describe their migraine. The interviews consisted of one or two broad questions that encouraged the participants to freely tell their experiences. The following questions were used in each study, Study I: Please tell me about your experience of living with migraine. Study II: 1) Please tell me about your experiences managing your life with migraine, and 2) Please tell me what you do to feel well. Study III: Please tell me about your experiences of attending physical therapy for your migraine. Study IV: Please narrate your experiences of receiving acupuncture treatment. Start with the beginning of your most recent treatment set and continue to where you are now. There are no right or wrong answers, so feel free to tell everything.

During each interview, I wrote notes to remember and follow up on details throughout the interview. The notes helped me to pose subsequent questions, to clarify experiences and to ask for more examples of their experiences. To encourage the participants to further deepen their narratives, I asked questions like, "How did you feel then?" and "Can you tell me more about...?" In studies I, II and III, it was a challenge to help the participant to tell their experiences as lived, and not only describe their beliefs and thoughts. When a participant started to generalize, I tried to gently guide him or her back

to the concrete experience by asking questions like, “Can you give an example...?” or “What was it like...?”

The 11 persons with migraine who participated in study III were also included in study II. The interviews for the two studies were performed on the same occasion. After answering the background questions and describing their migraine, the interview continued with the study III questions. When the interview reached the point when the participant had nothing more to add about their experiences of physical therapy, the interviewer continued by asking questions related to study II. However, it was natural for them to recall more experiences related to physical therapy, the topic of study III, from time to time during study II, and I encouraged them to describe these experiences. The length of the interviews varied, but on average, they lasted 150 minutes in study I, 80 minutes in study II, 40 minutes in study III and 50 minutes in study IV.

The participants were asked to draw a picture of their experience of living with migraine (study II) and of physical therapy (study III) when they had nothing more to add to their narration. I started by explaining that the drawing was totally voluntary and that the purpose of creating a picture was to help them recall and express their experiences. I explained that the picture itself would not be included in the analysis and that they could keep the picture afterwards. However, some of the participants hesitated to actually draw a picture, expressing that they did not have drawing skills. In the end after thoughtful consideration, 17 of 21 participants chose to create a drawing. After they had finished their drawing, the interview continued with a narration about the picture, starting with the questions, “What is in the picture?” and “What feelings and associations do you get when you look at the picture?” The drawing made the participants deepen their stories, by giving more examples of their lived experience or by telling more about the examples they had already given.

Because of this procedure the interviews were twice as long as they would have been if drawings not had been used. After the interview, all the participants offered to let me keep the picture, and almost all of them stated that creating the drawing was actually fun. They were assured that their pictures would not be reproduced, or displayed without their permission. Most of the participants, who made a drawing expressed that the drawing drew attention to experiences that they would not have been able to communicate otherwise.

Data analysis

Hermeneutic-phenomenological data analysis

During the analysis for studies I, II and III in this thesis, I tried to adhere to van Manen's (1997) explanation of hermeneutic-phenomenological research as "a search for the fullness of living" (p. 12). This was understood as the different ways a woman with migraine can possibly experience the world as a woman with migraine (I), the different ways a person with migraine can experience managing life to feel well as a person with migraine (II) and the different ways a person can experience physical therapy as a person with migraine (III).

The analysis involved interrelated phases of seeking meaning, analyzing themes and interpreting with reflection. These tasks were not performed in a stepwise fashion; instead, the analysis involved back and forth movement to reach an understanding of the phenomenon. The analysis started with a verbatim transcription of the recorded interviews, which was followed by rereading the transcripts of all interviews several times to gain a sense of their collective meaning. These meanings were written down and discussed by all authors. During the theme analysis phase, the entire text was reread, and the phrases and sentence clusters that seemed to be meaningful were marked as a meaning unit.

Van Manen (1997) describe the search for understanding a phenomenon, stating, “A true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance” (p. 32). Therefore, we asked the following question about each meaning unit: “What does this meaning unit reveal (thematically) about the lived experience of the persons with migraine?” We also tried to remain true to van Manen’s (1997) description of the “inventive thoughtful” attitude (p. 34) by reflecting on the data that I had started writing down and then alternating between reflection and rewriting in a back-and-forth process. The process of writing and rewriting is a complex process of thinking and re-thinking, reflecting and recognizing, and Van Manen (1997) states that “writing teaches us what we know and in what way we know what we know” (p. 127). To do justice to the fullness and ambiguity of the participants’ experiences, the process continued in a constant movement back and forth between the transcribed interviews and the text (produced as preliminary findings) and between the parts and the text as a whole. Through the process of analysis and reflective writing, our understanding evolved, and the final structure emerged.

The findings of a phenomenological study are not only based on the empirical world; they also derive from the researcher’s consciousness of the empirical world (Drew, 2004). Therefore, a great amount of time was spent exploring my own pre-understanding, assumptions and suppositions to stay open to the lived experiences of the persons with migraine. During the analysis for all three studies, my supervisors and I held numerous discussions about our understanding of the interviews, the preliminary findings and our pre-understanding and assumptions connected to the participants’ experiences. A record was maintained of our thoughts to facilitate openness throughout the process. I also involved both fellow doctoral students and senior researchers

who were experienced in qualitative methods in the discussions about our preliminary findings to help us understand how our findings could be interpreted and to challenge our evolved understanding.

During the data analysis for studies II and III, I became aware of Drew's (2001) suggestions for structuring pre-understanding. Motivated by a sincere desire to further explore our pre-understanding related to these particular studies, we engaged in the following steps. We started to explore our own feelings and motives that steered our choices of meaning units. I made a document that contained all of the meaning units from the interviews and arranged them in a column. In the next column, I wrote statements about the meaning units that triggered my interest or gave me a particular feeling. My co-authors then added their statements. These statements revealed the ways in which we understood the text. Having read and sometimes rewritten the statements, we tried to capture the questions that the statements answered. These questions revealed a substantial amount about our horizon of understanding. The next step was to add our own experiences related to the written statements (e.g., particular situations where we had been a patient or a caregiver) and the feelings connected to these experiences. This procedure made us aware of our feelings and the silent knowledge we carried with us, and it made us aware of new aspects of ourselves. Drew (2001) explains, "Researcher self-awareness means discovering, in the act of perceiving the phenomenon under investigation, the deep, foundational basis of personal meaningfulness that is always implicitly present in one's research interests" (p. 20). The questions and the summaries of the statements and uncovering our own experiences connected to the participants' experiences provided information about our collective understanding and presumptions. Making our pre-understanding and

assumptions explicit opened our minds to more ways of understanding the experiences of the participants.

Qualitative content analysis

The analysis of the interview text for study IV was inspired by Burnard (1991), who described the analysis in 14 steps. The analysis started with a verbatim transcription of the recorded interviews, and then the interviews were read several times to gain a sense of their content. Notes about important content were written in a separate document. Next, the interviews were read to create coded sections guided by the aim of the study. The coded sections were condensed into one or a few sentences to make it easier to grasp the main point of the content. Next, the condensed coded sections were sorted and coded into 156 codes that were very close in meaning to the original text. The codes were grouped together into subheadings and categories. The categories were created according to the requirement that they be meaningful and exhaustive in relation to the aim of the study. To understand the names of the categories and to verify whether any information that was important to the aim of the study had been left out, I read the transcribed interviews again. The preliminary findings were read to ensure that no information could be included in two or more subheadings or in two categories.

During the analysis, the sixth step outlined by Burnard (1991) was modified by discussing the content of the categories with two colleagues separately, and minor changes were made to reach consensus. Step 11 was omitted, because I agreed with Morse, Barrett, Mayan, Olson and Spiers (2002) that the quality of the study is not necessarily enhanced by having the participants verify the result. The steps described by Burnard (1991) were not performed in a step-wise fashion. Instead, the analysis went back and forth

between the steps, and a substantial amount of time was spent on writing and rewriting to obtain a sense of the data and to assure that all of the experiences of the participants were presented. Regarding the authors' impact on the research, Burnard (1991) suggested that they should offset their own biases and subjectivity when performing the analysis. However, even if an effort was made to stay close to the experiences of the participants to ensure that their views are presented, I believe it is impossible to avoid using one's pre-understanding while conducting a qualitative research analysis. For example, the process of grouping codes together into subheadings and categories is inevitably an interpretive process that is affected by the understanding of the researcher.

Ethical considerations

Studies I- IV were performed in accordance with the principles of Swedish law for research ethics (SFS 2003:460 §3 and 4) and in accordance with the World Medical Association's Declaration of Helsinki (World Medical Association, 2008). In addition, studies I, II and III were approved by the Regional Ethical Review Board at Umeå, Sweden (Ref. no. 08-182M). In this thesis, I have considered the following ethical research principles.

Obtaining informed consent

Before giving their informed consent to participate in any of the studies, the participants received written information about the project, including information about the aim of the study, what the interviews meant and that they would be recorded and information about the people responsible for the project. They were also informed that their participation was voluntary and that they could change their mind about participating at any time without having to

provide an explanation (cf. Kvale & Torhell, 1997). In addition, participants who were recruited via physical therapists were informed that their rehabilitation would not be affected based on whether they participated. When they registered their interest to participate, I provided them with an oral description of the project and answered their questions before they gave their written consent to participate.

Protecting anonymity and confidentiality

In all four studies, the participants were informed that the collected data would be handled in such way that no one outside of the project staff would be able to identify any of the participants. They were further informed about our intention to use citations from the interviews when presenting the findings and that the information in these citations would not be connected to any specific person. The judgment was made that the information in the interviews was sensitive enough to promise confidentiality and an anonymous presentation of the findings. To keep the promise about confidentiality, in accordance with Easter, Davis and Henderson (2004), the recorded data were kept in a locked space with no names on them. The place where the interview is held is important to assure confidentiality, both to ensure that other people would not know that they were participants and to ensure that the interview occurred in an undisturbed room. The time and place for the interview were chosen in accordance with the participants' wishes. They either invited me to their home or workplace, or they accepted my invitation to conduct the interview at the university.

When transcribing the text from the recorded interviews, all identifiable information that they gave, such as the names of people and places was omitted. In studies III and IV, the participants shared their experiences of physical

therapy and any information that could be traced to a specific clinic or physical therapist was removed to reduce the risk that any physiotherapist or participant could be identified. According to Oliver (2003), it is important to protect third parties, especially persons with titles, so it is not possible to trace them by using the exclusion method. We also addressed this issue by contacting physical therapists from a large geographic area and including many clinics that were similar to each other. To keep the interviews separate, I assign each transcribed interview a number. The documents with written consent papers were locked in a file cabinet separate from the tape-recordings and the USB drives.

Valuing the risk of harm

There was a potential risk that the study participants might find the study distressing or feel discomfort while talking about their experiences during the interview. Because a qualitative research interview is not an open conversation between equal partners (Kvale, 2006), it was important for me (the interviewer) to do as much as I could to minimize the risk of harm (cf. Oliver, 2003). To make the participants feel comfortable, I was especially vigilant in the situations when the participants showed signs of being sad or when they cried. In these situations, I offered them a chance to take a break and to turn the recorder off, but the participants never felt that it was necessary to do so. After the interview, I told them to contact me if they had any questions or if they needed to talk to me. However, only one woman contacted me, and she told me about a picture she would draw if she were invited to be interviewed again. Altogether, I believe that the knowledge provided by this thesis exceeds the possible risk of negatively affecting the participants throughout their participation.

FINDINGS

The findings of the four studies included in this thesis are based on the experiences of persons living with migraine. The findings include perspectives about the meaning of living with migraine and managing life to feel well and perspectives about the participants' experiences of physiotherapy and acupuncture treatment.

Living life with migraine

Living in uncertainty and striving for control

Living life with migraine meant living with the perpetual threat of being incapacitated by a migraine attack, which led to a life of uncertainty (I, II, IV). The attacks were unpredictable and could come without notice. The experience of having a migraine attack was understood as being besieged by an attack. The pain and the associated symptoms of the attacks affected the whole person and were so incapacitating that they were unable to function properly. The sense of being incapacitated by the attack derived from the severe pain in the head and also from nausea and vomiting, visual impairment, communication problems and increased sensitivity to light and noise. The attack often gave the sense of being unable to think by having reduced capacity to concentrate; in addition, the need for bed rest temporarily isolated the person from life. Being temporarily incapacitated by a migraine attack put the persons in vulnerable situations; some experienced the fear of being unable to take care of themselves when their vision was impaired, for example. The uncertainty about being able to function and thereby fulfill obligations during an attack led to a reluctance to plan ahead and to have dreams about the future (I).

The persons with migraine felt that they lacked control over their migraine, because they did not always know what caused the attacks and thus could not always prevent the attacks. They also felt ruled and directed by the migraine, in the sense that they had to avoid triggering the attacks and that migraine attacks sometimes prohibited them from doing activities (I, II, IV). To manage their lives with the uncertainty of migraine, the persons constantly struggled to maintain and increase their control over the migraine (I-IV). To increase their sense of control over migraine, they strived to build a foundation of safety by being able to avert the threat of migraine attacks and by having access to efficient ways to alleviate the symptoms of the attack. When they had efficient ways of alleviating the attack, it increased the participants' ability to be in control of their lives by making it possible to function during an attack (II). Women whose migraines were alleviated by acupuncture treatment expressed that they were able to live life to the fullest again. They felt that acupuncture treatment gave stability to the unpredictability of migraine; therefore, they dared to try more activities without being afraid of triggering a migraine, which gave them a sense of freedom (IV).

Not knowing when the next migraine attack would occur put the persons in a state of constant readiness for an attack, which was understood as a way of striving for control. Being constantly ready meant considering the risk of exposing oneself to a trigger or the consequences of having an attack before engaging in an activity. It also meant constantly watching for signs of an attack and being prepared to manage an attack when it hit them (I). The persons with migraine used their experiences of triggers as a guide and made adjustments in their everyday lives to manage them. The triggers varied; some triggers were possible to control, and others were not. In addition, the participants experienced different degrees of sensitivity to triggers and having a low energy level was

considered to increase the risk of triggering a migraine attack. These experiences guided them to eat at regular times, to cherish a good night's sleep and to perform activities that increased their energy (II). A strong sense of well-being tended to increase their tolerance for migraine attacks and also made it easier to handle them. With the security of being able to function during an attack, the participants were able to focus more on the activities that made them feel better, instead of focusing on things to avoid. Therefore there was a connection between having a foundation of safety and being able to amplify the positive aspects of life. Having a foundation of safety was understood to allow another level of freedom and possibility in life (II).

To prevent or alleviate the migraine attacks persons with migraine primarily used prescription medication because it was considered a quick and easy way to be able to function. The feeling of control was enhanced by having medicine that worked well because it could prevent the most severe migraine symptoms. However, medication also caused the persons to worry about the possibilities of being negatively affected by long-term use, becoming addicted and the medication losing its effectiveness after too much use. These contradictory feelings about medication made them hesitate and negotiate with themselves before taking medication. Thus, medication could increase the sense of control, but simultaneously, it added to the feeling of living life with uncertainty (I, II).

Another way to increase their sense of control was exercising, which was a common way to increase well-being and to increase tolerance to migraine, in the sense that it decreased muscle tension, lowered stress and left a pleasant feeling in the body. Some of the persons with migraine had tried cognitive behavioral therapy or mindfulness training and found these approaches to be helpful for handling the sense of uncertainty in their lives. They felt more joy

when they focused on the possibilities instead of the limitations that migraine caused, and being in the present between the attacks decreased their worries and helped them enjoy life more (II). When they attended physical therapy and it was effective in decreasing their suffering from migraine, it gave them a sense of control over their migraine and a sense of safety. Therefore, it provided psychological and existential relief. For example, some of the participants expressed that they felt that they were entering a new phase in life when the migraine disappeared or that they were no longer restricted by migraine in the sense of having to live a very structured life. Relief from migraine also meant having new opportunities to participate in activities that had triggered migraines in the past (III, IV).

Living in the shadow of doubt

Central to almost all of the participants' narratives about living with migraine in studies I, II and III was the notion of being misunderstood or mistrusted. Living with migraine meant living with an invisible disorder that was sometimes questioned by others. The persons with migraine lived with the notion that migraine was perceived by the general population as being the same as a headache (i.e., an insignificant problem). They had experiences when others did not understand the intensity of the attacks or the lifestyle adjustments they made to avoid triggering migraine, which made the persons live in fear of not being believed or judged as lazy or weak. They struggled to avoid being doubted by pushing themselves to continue working while having an attack. The threat of being doubted made the persons hide their symptoms and resist telling others about their migraine. When the persons with migraine were met with distrust, they found it more difficult to come to terms with their situation (I).

All of the persons with migraine talked about acceptance, and some of them described their acceptance of migraine as merely knowing that they suffered from it. They expressed frustration about the limitations imposed by migraine in their lives and often compared their lives to the “normal” lives of others or to the time before they were afflicted with migraine. Their frustration was understood as an expression of not being able to meet the demands they placed on themselves when migraine repeatedly interfered with their lives (II).

However, when they felt that they were being understood and believed, the persons with migraine found it easier to accept being afflicted with migraine and were better able to handle their migraine (I, II). For example, sensing others’ confidence could result in less pressure to hide the symptoms and enabled the person with migraine to take the time to recover, something that helped prevent future migraine attacks (I). Understanding attitudes among influential people in their lives, such as loved ones, employers or healthcare personnel, were especially important in the process of accepting migraine as a part of life. The persons who had made peace with being afflicted had acquired a sense of security that made them less dependent on others’ thoughts about migraine. There was no guilt to rule them as it had before. They experienced a feeling of “being on a plateau” from which they could view more possibilities and from which the migraines did not preoccupy them as much as they had before. Furthermore, reaching acceptance and finding peace in being afflicted enabled them to find more ways to amplify the good things in life. The persons’ inner sense of acceptance, however, was not stable; instead, it fluctuated to some extent depending on the attitudes of the surrounding people (II). This experience was understood as living in the shadow of doubt.

Attending physical therapy

Investing time in one's health

By attending physical therapy, the persons with migraine invested time and energy in decreasing the migraine attacks and thereby in feeling better. The time spent interrupted daily activities, which could be frustrating but also provided an opportunity to focus on oneself. Even if using medication was seen as an easy solution, a strong motive to participate in physical therapy was a desire to decrease the use of medication, and for those participants who were not satisfied with their medication, it was a possible way to alleviate the symptoms (III, IV).

To invest the time and energy necessary for physical therapy, it was important that the interventions provided the reward of improved health (III). Physical therapy, including acupuncture, was experienced as a way to improve health and well-being, often by decreasing the number of migraine attacks and lowering their intensity. In addition, the persons with migraine described feeling more energy, feeling relaxed and experiencing an alleviation of pain in other parts of the body. When physical therapy was effective, it was considered a natural way to heal the body instead of taking medication (III, IV). Women receiving acupuncture treatment spoke about experiencing mental relaxation in conjunction with feeling more focused after a session (IV).

Wanting to be seen and sensing trust

See me, understand me and be trustworthy. These aspects of the interaction with the physical therapist were emphasized by the persons with migraine. These aspects were considered equally important to the appraisal of the physical therapy intervention, i.e., to what extent the intervention was perceived as improving their health (III).

The persons with migraine found it crucial to be understood and trusted by the physical therapist. Sensing trust enabled them to communicate freely with the physical therapist and imposed a sense of being seen as a whole person. On the contrary, when the participants felt that they had not been taken seriously by healthcare professionals, they felt invisible or unworthy of the professional's time. The sense of being understood was mediated by communication and the therapist's actions (e.g., showing caution and being attentive to the reactions of the person with migraine). The person felt acknowledged and important when the physical therapist remembered previously expressed needs, requests or personal information. It was hard to start over with a new physical therapist when they had become acquainted with a physical therapist who knew their history (III).

When attending physical therapy, the persons with migraine felt that they had to rely on the competence of the physical therapist and emphasized the importance of his or her knowledge and skill. Having confidence in the physical therapist was important to feel secure, and confidence was mediated by the physical therapist's personal manner, i.e., way of acting, touching and communicating. The physical therapist's use of touch was especially highlighted because it provided the person with migraine with the sense that he or she knew what to do (III). It was important that the physical therapist was calm and that he or she showed interest in the women with migraine; when he or she could incorporate a sense of calmness, the acupuncture treatment was described as having a better effect and being less painful when the women were relaxed (IV). The perceived outcome of physical therapy, including acupuncture, was improved when they had confidence in the physical therapist and felt secure (III, IV). However, the relationship between confidence and outcomes also worked in the opposite direction: a good outcome of the intervention increased the sense of

confidence in the physical therapist. It seemed that the knowledge and skills related to performing the intervention were more important than knowledge about the disorder (study III).

The persons with migraine began physical therapy with individual needs; some wanted to be guided to be better able to cope with migraine by themselves, and others needed to be taken care of, for at least a little time, until they got better. They wanted to be treated as an individual when attending physical therapy, which meant that they wanted to be seen as a whole person, not just a person with migraine, and treated like anyone else with migraine. Therefore, it was important that the persons with migraine were not treated by rote but instead were treated with individual approaches (i.e., had an intervention that was adapted specifically for them). It was also important to become involved in the physical therapy (e.g., by learning more about the interventions and providing feedback). However, the need to be part of the decisions, like the choice of interventions, changed during the therapeutic process according to the amount of trust the person with migraine had in the physical therapist. It was preferable to have collaboration in the decision-making process and at least to be asked before anything changed. The availability of physical therapy was important, and when it had been assured in advance, it offered a sense of comfort and security that made it possible to cope with migraine better (III).

DISCUSSION

The overall aim of this thesis was to describe and develop an understanding of persons' experiences of living with migraine and managing life to feel well, and to elucidate their experiences of physical therapy. The findings build on the voices of persons with migraine and are to be understood as possible ways of being in the world as a person with migraine and ways of experiencing physical therapy.

In papers I, II and IV, the findings showed that living with migraine means living in uncertainty of when or how incapacitating the next attack might be. It is not possible to understand this uncertainty if one does not understand the experience of a migraine attack. A migraine attack was experienced by persons with migraine as being incapacitating to the extent that it was impossible to fully function and participate in life, and thus understood as being besieged by pain and other associated symptoms. During an attack the person felt dominated by their symptoms and were forced to postpone everything else to address their migraine (I). These findings can be compared to the findings of a recently published study (Ramsey, 2012) that interpreted the pain of a migraine attack as torturous based on the participants' descriptions of the pain as a "freight train coming through", "like a storm entering my head" or more often, as if their "head would explode" (p. 302). The pain was magnified by light and noise and forced the person with migraine to stop all activity and focus on themselves to obtain relief. Although it is impossible to fully understand the experiences of another person, the incapacity and pain can be imagined.

When attempting to understand the experience of a migraine attack, it is possible to begin to understand the worry caused by the anticipation of an attack. The present findings showed that the impact of migraine became more evident when the symptoms of the migraine disappeared or was lessened. The persons

described the security of a migraine free period as the ability to live life to the fullest, and they felt free to do things that previously triggered migraines (III). Furthermore, the persons' sense of acceptance of being afflicted, affected their experience; those who felt peace with being afflicted described this as a foundation from which they perceived more possibilities (II). These experiences can be understood as they felt empowered when migraine interfered in their life to a lesser degree than it had previously. Aujoulat, Marcholongo, Bonadiman, and Deccache (2008) argued that empowerment is a process that involves gaining control as well as relinquishing control, which enable patients to come to terms with their illness.

A sense of control was central to the experiences of persons living with migraine and was considered necessary for these persons to feel well (I, II, IV). According to Skuladottir and Halldorsdottir (2008), the main challenge for women with chronic pain is to maintain a sense of control over themselves and the pain and to maintain a positive self-image and self-esteem despite their pain. Persons with migraine strived to control their migraine triggers and the symptoms of their attacks (I, II). However, they also fought a sense of being ruled by the migraine, resisting the idea that their migraine controlled their activities through the threat of triggering migraine attacks (I). Possessing effective ways of alleviating attacks were understood to increase the sense of control over one's life and to reduce the feeling of being ruled by migraine by improving function during an attack (II, IV). Heath, Saliba, Mahmassani, Major, and Khoury (2008) found a connection between possessing effective pharmaceutical therapies and sensing internal locus of control among persons with migraine. Thus, it is reasonable to believe that when an attack no longer imposes a significant threat of incapacitation, the sense of control increases. However, the findings of this thesis suggest that this relief does not have to

come from pharmaceuticals; the relief may also be achieved with physical therapy or acupuncture treatment (III, IV).

Having control over the attacks was a prerequisite for persons with migraine to focus on increasing their general wellbeing and to experiment with triggers. A lack of control forced them to concentrate all their efforts on averting attacks (I, II). When persons with migraine challenged the limitations imposed by their triggers, their lives were enriched, and they were able to pursue more activities (II). The findings indicated that the persons' sensitivity to migraine triggers may vary (I, II). When they had a high sense of energy, they experienced greater tolerance of migraine triggers. Therefore the persons with migraine attempted to increase their sense of energy and joy, by amplifying the positive aspects of their lives (II). This finding has not been so evident in previous research. In Ramsey's (2012) study, however, participants noted that in an attempt to prevent migraine attacks, they engaged in activities that brought them joy. Persons with migraine experienced that by attending physical therapy, acupuncture treatment or participating in other activities that increased their sense of general wellbeing, their sensitivity to migraine triggers decreased (II, IV). If a high sense of energy can prevent migraines and increase the sense of control over migraine, it would be beneficial for healthcare personnel to focus on promoting strategies to increase positive aspects of life and their well-being, rather than concentrating only on averting migraine attacks.

All four papers included in this thesis indicated the need to be trusted. In study I, trust is obvious as finding in a main theme. In study II, trust is important in the process of acceptance, which is promoted by the action of the surrounding people. In studies III and IV, trust is emphasized as an important part of the patient-therapist relationship. The stories told by persons with migraine involving their fear of being mistrusted can be described metaphorically as

living in the shadow of doubt and understood as living with stigmatization. Stigmatization is a social phenomenon in which persons with certain attributes, for example, are viewed negatively by others in the same social context (Goffman, 1990). The findings showed that persons with migraine felt that other people compare their migraine symptoms to an “ordinary headache” and that these symptoms are therefore perceived as an insignificant problem that should not preclude activities (I). Previous research has shown that the seriousness of a migraine attack is sometimes questioned by other people, and this contributes to feelings of being mistrusted and doubted among persons with migraine (Cottrell et al., 2002; Moloney et al., 2006). To cope with the feeling that others might judge them as lazy or weak, the persons with migraine hid their symptoms, and pushed themselves to avoid being mistrusted (I). Goffman (1990) describe that being stigmatized may make it difficult for a person to accept the attribute that is the cause of the stigmatization, which produces feelings of shame.

The finding showed that the persons who had come to terms with being afflicted, experienced less guilt and migraine did not rule them as it had before (I). According to Aujoulat, Luminet, and Deccache (2007), persons with chronic illness must manage changing self-representations or self-images, and they often ask themselves, “Am I still a normal person despite my illness?” (p. 781). The authors further argued that to feel empowered, patients must come to terms with their threatened sense of security and identity. Therefore, achieving peace with being afflicted can be seen as a process of empowerment that provides internal security. This internal sense of security enabled the persons with migraine to perceive more possibilities and prevented their migraine from demanding as much attention in their lives (II). The findings in this thesis showed that a state of peace with being afflicted was not a constant state; it could change depending on the attitudes of people in the surroundings (II). This finding can be compared

to Paterson's (2001) shifting perspectives model of chronic illness, which attempts to explain people's variation in their attention to symptoms over time. Sometimes, persons with chronic illness consider wellness as being most prominent of their world and sometimes they consider illness most prominent, depending on which context they are in (ibid). The finding about having peace with being afflicted is in line with Chiros and O'Brien (2011), who found that people's acceptance of their migraine pain affected their sense of control over the role of migraine in their lives.

Although acceptance affects the experience of living with migraine, as implied by the findings in this thesis, it is an aspect that has received limited attention in migraine research. Chiros and O'Brien (2011) found that people's acceptance of their headache pain affected the extent to which migraine interfered with their pursuit of important life goals and was connected to their levels of activity and pain-related interference. A study by Mo'Tamedi, Rezaemaram, and Tavallaie (2012) showed that Acceptance Commitment Additive Therapy, which can be described as a combination of mindfulness and acceptance therapy, significantly improved headache disability, emotional distress and the affective dimensions of pain among persons with chronic headache, including migraine. Although there is a need for further research on the meaning of acceptance among people living with migraine, the findings of this thesis indicate the importance of acknowledging this aspect in the treatment of persons with migraine.

A strong motivation for attending physical therapy among persons living with migraine was the potential to increase their health by decreasing the duration and intensity of attacks and the use of medication (III, IV). Likewise, it was equally important to be seen, understood and sensing confidence in the physical therapist. In previous research on physical therapy, Melander-Wikman

(2008) found that empowering relationships enable clients to have self-control and to develop a positive view of themselves. The process of empowerment in a person with a chronic illness may be facilitated by healthcare providers through a change in approach from disease management to the recognition and acknowledgment of the illness experience (Aujoulat et al. 2008). The persons with migraine in this thesis, wanted to be treated as individuals (III), and part of this experience was being listened to and being met as a unique person. Skuladottir and Halldorsdottir (2008) state that healthcare personnel are potentially powerful people who can influence individuals' means of managing their chronic pain. The authors emphasized the importance of healthcare personnel in facilitating the sense of empowerment among women with chronic pain, which included strengthen their self-esteem and self-image and help them accept their own limitations. Therefore, to facilitate the sense of empowerment, the physical therapists should involve the persons with migraine in the rehabilitation and provide individually adapted interventions.

The present findings showed that the persons' confidence in their physical therapist and their sense of being respected, involved and treated as individuals were related to the physical therapist's communication skills (III). The importance of the physical therapist's ability to communicate has been emphasized in several earlier studies (Cooper, Smith, & Hancock, 2008; Kidd, Bond, & Bell, 2011; Potter, Gordon, & Hamer, 2003a; Slade, Molloy, & Keating, 2009). Rohrer, Wilshusen, Adamson, and Merry (2007) concluded that a patient-centered communication style can empower patients. In this thesis, being trusted and understood by the physical therapist was highlighted by the persons with migraine and was considered a key to communication (III). According to Dekker et al. (2012), being taken seriously about the burden of migraine was one of the most important aspects when meeting general

practitioners, and it was found that empathetic listening conveyed trust and understanding. To understand other people's situations, it is vital to focus on their experiences. Kierkegaard (1998) noted the following, "In order to truly help somebody else, I must understand more than he - but certainly first and foremost understand what he understands. If I do not do that, than my greater understanding does not help him at all" (p. 45). This creates a need for healthcare professionals to take the time to listen to persons with migraine and to acknowledge their individual experiences and needs. Cott (2004) found that to improve rehabilitation, personnel need to reflect on the individual needs of their clients, in addition to, involving them in goal-setting and decision-making.

Equally important as being understood was having confidence in the physical therapist, which was mediated through communication and, primarily, through the physical therapist's touch (III). According to Halldorsdottir (2008), patients in nursing do not connect with their nurse if they do not trust him or her, which includes being perceived as competent and wise as well as being perceived as caring about the patient. A high-quality patient-therapist relationship that is built on this connection is empowering for the patient. In this thesis, persons with confidence in their physical therapist had a decreased sense of worry and fear (III, IV). This finding can be compared to the findings of Kidd et al. (2011), who argued that within a good therapeutic relationship, confidence in the physical therapist as well as the therapist's expertise and self-confidence can create a confident patient.

Although more research is needed on the relationship between persons with migraine and physical therapists, the findings of this thesis indicate that physical therapists might improve their practice by reflecting on their actions to convey understanding and trust and to instill confidence. According to Tickle-

Degnen (2002), research on the therapeutic relationship in rehabilitation can shape an evidence-based practice, and this thesis can contribute to this process.

METHODOLOGICAL CONSIDERATIONS

In qualitative research, it is common to use Lincoln and Guba (1985) criteria for assessing trustworthiness. However, I agree with Norlyk and Harder (2010) that in phenomenological research, there are aspects of quality other than those proposed by Lincoln and Guba (1985) that must be considered. Norlyk and Harder (2010) argue that to assess the quality of a phenomenological study, the study must include clarification about how the philosophical underpinning has been implemented (such as how lived experience and phenomenon are defined and how the researchers have kept an open mind). Therefore I have mainly chosen to discuss the suggested criteria for quality in phenomenological research according to Norlyk and Harder (2010) in studies I, II and III. In addition, I have used Graneheim and Lundman's (2004) criteria for quality in content analysis to assess the quality of study IV.

In choosing sampling strategies, Norlyk and Harder (2010) stress that it is most important that the participants have experience of the phenomenon and that it is less important that they vary in characteristics such as age and gender. Graneheim and Lundman (2004) state that it is necessary to collect various experiences of the studied phenomenon and that variations in age and gender can contribute to a richer variation of experiences. In all the studies, our intention was to include both men and women; however in studies I and IV, only women participated. Because every participant who volunteered to participate was invited, we did not put much effort into obtaining greater variation than we received. However, the richness in the interviews in all studies indicates that the participants had many experiences of the phenomenon in each study.

Even though Norlyk and Harder (2010) argue that demographic information is more important in empirical research than in phenomenological research, I find it important to report aspects that could affect the results of the

studies. For studies I and II, we contacted the Swedish Migraine Association, who supported us by forwarding letters about the studies to members in northern Sweden. Being a member of this association could indicate that these individuals were more active in handling their migraine; however, during the interview, the participants stated that their only engagement in the association was reading the membership magazine. In study II we also included persons who were recruited by physical therapists. Attending physical therapy could mean that the individuals were dissatisfied with their medication, a finding from study III that could impact their experiences of managing life to feel well. By recruiting persons from different contexts, we intended to collect a variety of experiences. In studies III and IV, we chose to invite participants who were receiving ongoing treatment at the time of the interview. This choice was based on the perception that being in ongoing treatment would make it easier for the participants to narrate their lived experiences of physical therapy and answer questions about their acupuncture treatment. This assumption is based on the perception that attending physical therapy is not significant enough event in life for one to remember many details after finishing a set of treatments. However, the tradeoff may be that distance in time and having experienced and completed series of treatments can offers a greater opportunity to reflect on the process and the outcome. Nevertheless, many of the participants had experienced several treatment sets, which made it possible for them to narrate their experiences of previous treatments. Those participants who did not have that experience spoke about the process and outcome they had experienced so far. Moreover, an additional limitation of the participants' involvement in ongoing treatment could be that the persons with migraine were dependent on the physical therapist, which could make it more difficult to speak freely about the relationship with him or her.

In this thesis, narrative interviews were conducted to fulfill the aims of the studies (cf. Bates, 2004). In studies I, II and III, we wanted the participants to narrate their lived experiences of the phenomenon under study, and van Manen (1997) emphasized the need for the interviewer to have a clear interest and research question. Furthermore, Norlyk and Harder (2010) emphasize the importance of having a clearly defined phenomenon. Otherwise, there is a risk that the interview could produce data that contain many short responses with little depth or that contain an unmanageable number of experiences that lead in every direction and nowhere in particular (van Manen 1997). Undoubtedly, my interviews with the participants became richer and deeper, and also more focused over time. To enhance the quality of the next interview, I always transcribed the interview as soon as possible and reflected with my co-authors about their quality and the possible ways of asking questions. This process helped me focus on the aim of the study, guided me to ask questions that encouraged a deeper narrative about lived experiences and helped me to be quiet to encourage the participant to tell more of his or her story.

Including the drawings as a method to facilitate the interviews was fruitful and increased the quality of the interviews. During the analysis of the texts, we found that the text produced after the drawing often included more feelings and was more nuanced and better expressed. This finding is in line with Harris and Guillemin (2012), who found that approaches that stimulate the interviewee's senses (like drawings) can enrich the interviews allowing the interviewee to express unexplored aspects of their illness or health care experiences. Furthermore, Guillemin (2004) concluded that drawings enable a broader and more in-depth exploration of the experience of illness and that drawing is a valid method of knowledge production, especially in conjunction with the participants' narrative about their drawings.

A challenging and essential aspect of quality, according to Norlyk and Harder (2010) and Drew (2001), is keeping an open mind to all the experiences of the study participants and not letting pre-understanding lead to premature interpretations. During the research process for all four studies, my supervisors and I held numerous discussions and made notes about our pre-understanding and presumptions. In addition, during the process of writing the findings of the studies, we had discussions about the preliminary findings with researchers who were experienced in qualitative methods (some of whom also lived with migraine). Van Manen (1997) notes the benefits of using collaborative discussions of the preliminary themes to generate deeper insights and understanding. This process can enable the researcher to re-interpret, make additions and deletions and finally reformulate the written text. When we conducted the study about managing life to feel well while living with migraine (II) and the study about the meaning of physical therapy among persons with migraine (III), our pre-understanding from the previous studies was apparent in the discussion. Furthermore, having our own experiences as a physical therapist, nurse and health consultant who had met with individuals with disabilities including those with migraine, it was crucial to try to make these sometimes unconscious presumptions explicit. Therefore we adopted Drew's (2001) suggestions for structuring our own pre-understanding, suppositions and assumptions, which enabled us to reflect more about our pre-understanding in connection with the participants' lived experiences. Not having experience of migraine myself or in any of the people in my immediate surroundings naturally affected my horizon of understanding, but it also made it easier to stay open and unprejudiced regarding the phenomenon of migraine. I consider it fruitful that my co-authors and I had different health-care professions as it enabled us to view the phenomenon from different perspectives.

Transferability is an aspect of trustworthiness that needs to be considered. According to Graneheim and Lundman (2004), it refers to the extent to which the findings could be transferred to others in a similar situation, to those participants who were included in the study, and they argue that it must be the reader's decision, even if the author could offer suggestions about this aspect. To enhance transferability, the research must describe the context, participants, data collection and analysis, and appropriate quotations are also useful. We have tried to include these components. However, in this thesis, the findings aim to increase understanding of the studied phenomenon by showing ways of being in the world as a person with migraine, and according to van Manen (1997) phenomenological research aims to increase thoughtfulness and encourages readers to act with more tact towards others. The transferability of the knowledge provided by this thesis could therefore be seen as an increased understanding that may encourage physical therapists and other healthcare professionals to reflect on their practice and be curious about the lived experience of each person with migraine.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Having a migraine attack means more than having a headache. The findings indicated that the experience of having a migraine attack can be understood as being besieged by pain and other associated symptoms that incapacitate and affect the whole person. Living with migraine means living with the uncertainty of having an attack, and to feel well, persons with migraine strive to increase their control over their migraine and find it especially important to have control over the attacks. By finding peace with being afflicted, persons with migraine received an inner sense of security from which they could view more possibilities than limitations in life. Therefore, it is important for healthcare professionals to take time to listen to the experiences of people who are living with migraine. Learning about their sense of control over migraine and their acceptance of being afflicted, opens up possibilities for individually adapted interventions and empowering actions.

The finding indicate that physical therapy, including acupuncture treatment, may be an option for persons with migraine to alleviate their migraine and to increase their well-being. The sense of well-being seemed to be related to the sense of being able to cope with the migraine attack, and a strong sense of well-being seemed to decrease the participants' sensitivity to migraine triggers and thereby decrease the number of attacks. Therefore, it could be beneficial to give the person with migraine tools to increase their sense of well-being in physical therapy, and as well evaluate their sense of well-being, in addition to addressing the frequency and intensity of attacks.

The findings showed that the relationship between the physical therapist and the person with migraine was essential, and the participants emphasized the need to be trusted, to be individually treated and to have confidence in the physical therapist. To improve these aspects of the relationship, the physical therapist could find insights by reflecting on the best ways to show the persons with migraine trust and understanding, how to involve them in treatment and how their actions could increase the person's confidence in them.

FURTHER RESEARCH

The findings of this thesis revealed new research avenues:

- Few studies have illuminated the meaning of control and acceptance when living with migraine. The findings in this thesis indicate a need of more research to increase the knowledge about the development of people's sense of control over migraine, and of their sense of finding peace with being afflicted.
- Only a few studies have mentioned the importance of well-being while living with migraine, and more research is needed to provide basic knowledge on this aspect in the treatment of migraine.
- There is a need for studies about the views of physical therapists toward treating persons with migraine. Increased understanding of their experiences can provide valuable information about practice.

SVENSK POPULÄRVETENSKAPLIG SAMMANFATTNING

Att sträva efter kontroll och acceptans för att må bra

– upplevelser av att leva med migrän och delta i sjukgymnastik

Att leva ett liv med migrän innebär att leva med ett funktionshinder. WHO har listat migrän som en av 20 diagnoser som orsakar mest funktionsnedsättning. Migrän är en kronisk, neurologisk sjukdom som drabbar ca 15-18% kvinnor och 6-9 % män. Symtom vid ett migränanfall kan variera men karaktäriseras vanligen av ensidig huvudvärk som varar mellan 4-72 timmar. I samband med huvudvärken är det vanligt med symtom som illamående, kräkning och ökad känslighet för ljud och ljus. Personer som har migrän med aura kan även få symtom som synbortfall, domningar och förlust av talförmåga.

Även om sjukdomen till synes bara verkar ge symtom i återkommande attacker av huvudvärk och associerade symtom så är inte perioderna mellan anfällen symtomfria. Det är vanligt att personer med migrän är oroliga inför nästa anfall och att denna oro påverkar och styr hur de lever sitt liv. De anpassar sitt liv för att undvika att utlösa migränanfall. Forskning har visat att kvinnor med migrän ständigt är på sin vakt för att upptäcka eventuella tecken på migrän eller närvaron av migränframkallande faktorer – triggers. Det finns olika former av triggers, en del går att kontrollera, t.ex. intag av mat och dryck medan andra inte är kontrollerbara, t.ex. väderomslag. Eftersom migränanfallen är oberäkneliga, påverkas även personens familj, arbete och det sociala livet. Forskning har visat att när effekterna av migrän även drabbar omgivningen så upplevs detta ibland som värre än själva symtomen av anfallet.

Vanligtvis behandlar personer sin migrän med läkemedel, både i förebyggande syfte och som akut behandling. Icke farmakologiska behandlingar rekommenderas också i nationella behandlingsriktlinjer för migrän, såsom biofeedback, stresshantering, akupunktur och kognitiv beteende terapi. Akupunktur som behandling har visat sig vara lika effektivt som placebotestad förebyggande migränmedicin. Dessutom har fysisk träning har visat sig ge positiva effekter även om mer forskning behövs inom det området. Det övergripande syftet med denna doktorsavhandling var att beskriva och utveckla en förståelse för personers upplevelser av att leva med migrän och av att hantera livet för att må bra samt att belysa deras erfarenheter av sjukgymnastik.

För att utforska och beskriva personers upplevelser av att leva med migrän och deras upplevelser av att delta i sjukgymnastik användes en kvalitativ design på studierna. Kriterier för att delta i studierna var att personen skulle ha en diagnosticerad migrän, vara minst 18 år och prata svenska. Svenska migränförbundet hjälpte till vid rekryteringen av deltagare till studie I och II och sjukgymnaster hjälpte till genom att ge information om studie II, III och IV till personer som de behandlade för migrän. Kvalitativa, berättande intervjuer genomfördes i samtliga studier. I två av studierna (studie I och III) ombads personerna även att teckna en bild av deras erfarenheter för att underlätta för dem att utveckla deras berättande i intervjun. För att tolka och förstå deras upplevelser av att leva med migrän (studie I), av att hantera livet för att må bra (studie II) och av att delta i sjukgymnastik (studie III) analyserades intervjuerna med en hermeneutisk fenomenologisk ansats. Studie IV analyserades med kvalitativ innehållsanalys för att beskriva deras upplevelser av akupunkturbehandling.

Resultaten i avhandlingen visade att leva med migrän innebar att leva i ovisshet. Det var en ovisshet om både när och hur allvarligt nästa anfall skulle

bli. Personerna med migrän strävade efter att öka känslan av att ha kontroll över migränanfallen och de försökte att identifiera och hantera triggers till migrän och att hitta effektiva sätt att lindra anfallen. Personer som upplevde att de hade tillräcklig kontroll över triggers och hade bra sätt att lindra effekterna av anfallen, upplevde att de hade en säkerhet som gjorde det möjligt att experimentera med triggers och såg nya möjligheter att öka sitt välmående. Resultatet visade också att känsligheten för triggers varierade. När personerna med migrän mådde bra och hade hög energi upplevde de att de hade en mindre risk att utlösa ett anfall. En hög känsla av välmående gjorde dessutom att de lättare känslomässigt kunde hantera anfallet.

Personerna med migrän bar på en oro över att vara missförstådda och misstrodda. De upplevde att migrän generellt i samhället uppfattas som ”vanlig huvudvärk”, som inte är funktionsnedsättande i samma grad som migrän. Därför var de oroliga att uppfattas som lata eller svaga när de inte kunde utföra sina aktiviteter på grund av ett migränanfall. Detta gjorde att de pressade sig själva att fullfölja sina åtaganden trots ett migränanfall. När de möttes av förståelse blev det lättare att hantera känslor av att vara drabbad av migrän och det underlättade för dem att finna sinnesro med att ha migrän. De personer som funnit denna sinnesro, upplevde en inre känsla av trygghet som gjorde att de kunde se fler möjligheter än begränsningar i livet. De upplevde också en minskad känsla av skuld när de t.ex. var tvungna att ställa in något för att de hade ett migränanfall, vilket gjorde att migränen inte påverkade och styrde deras handlande lika mycket som den gjort tidigare.

När personer med migrän deltog i sjukgymnastik, innebar det en investering av tid och energi för att må bättre. För att fortsätta med behandlingen var det viktigt att sjukgymnastiken resulterade i en känsla av ökad hälsa. Sjukgymnastik bidrog till att de ofta upplevde att migränen lättade och dessutom

kunde de också få ökad energi, avslappning och smärtlindring i andra delar av kroppen. Ytterligare fördelar var att sjukgymnastik upplevdes som ett sätt för kroppen att hela sig själv. Personer med migrän betonade behovet av att vara trodda och bli individuellt bemötta men också värdet av att känna förtroende för sjukgymnasten. Känslan av en förtroendefull relation gjorde det möjligt att prata fritt om allt med sjukgymnasten. Den bidrog också till att de kände sig sedda och inte bara som en person med migrän. Förtroende för sjukgymnasten skapades både i dialogen med henne eller honom och genom sjukgymnastens agerande. En känsla av trygghet och kunskap kunde förmedlas genom sjukgymnastens beröring.

Sammanfattningsvis så är kunskapen om innebörden av att leva med migrän viktig för sjukgymnaster och andra inom hälso- och sjukvård som möter personer med migrän. Personers upplevelser av migrän, som deras förmåga att kontrollera den och deras känsla av acceptans är viktiga faktorer. Genom att lyssna på dessa personers erfarenheter, skapas möjligheter att utforma individuellt anpassade åtgärder. Det ger också sjukgymnasten möjligheten att genom sitt agerande underlätta för personen att stärka sina personliga resurser och delta i beslut om mål och åtgärder för att öka välmående. Känslan av välmående tycks påverka både förmågan att hantera ett anfall och minska känsligheten för triggers. Därför är det av betydelse att de sjukgymnastiska åtgärderna inriktas mot att ge verktyg för ökat generellt välmående, förutom att minska anfallen. Då betydelsen av relationen med sjukgymnasten betonas av personer med migrän är det viktigt att sjukgymnasten reflekterar över hur hon/han kan inge förtroende och få personen att känna sig förstådd och involverad i behandlingen.

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Paper I

RESEARCH PAPER

Migraine – more than a headache: Women’s experiences of living with migraine

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Purpose: In this qualitative study the aim was to explore the meaning of living with migraine. **Methods:** In-depth interviews were conducted with ten women about their experience of living with migraine. Halfway through the interview, the women drew a picture of what living with migraine is like, and the interview continued with the conversation being guided by the picture. The interviews were analyzed using a hermeneutic phenomenological method inspired by van Manen. **Results:** The analysis revealed an essence “Being obliged to endure a life accompanied by an unpredictable and invisible disorder” and three themes “Being besieged by an attack”, “Struggling in a life characterized by uncertainty” and “Living with an invisible disorder.” **Conclusions:** Migraine is a debilitating disorder which accompanies life in the sense that it or the threat of its return is always present, and yet invisible to others. The struggle of enduring life with migraine is worsened by the feeling of having an invisible disorder and of being doubted. There is a need to increase the knowledge among healthcare professionals about what it means to live with migraine, something this qualitative study offers.

Keywords: Migraine, pain, qualitative research, women

Introduction

Migraine is a common disorder that affects three times more women than men [1]. This disorder is characterized by a cycle of painful headaches with associated symptoms such as nausea, photophobia or phonophobia separated by apparently symptom-free periods [2]. However, the effects of migraine are not limited to the periods of pain associated with an attack as, in the periods between one attack and the next, migraine sufferers might experience fear and anxiety in anticipation of the next attack [3]. Thus, migraine can be viewed as an ongoing cycle of suffering, because it involves treating the current attack and worrying about the next one [4].

In 2001, The World Health Organization (WHO) listed migraine as being among the top twenty causes of disability

Implications for Rehabilitation

- The meaning of living with migraine is experienced as having a debilitating disorder which accompanies life in the sense that it or the threat of its return is always present, and yet invisible to others.
- There is a need for healthcare professionals to increase their awareness of the meaning of living with migraine, to enable them to meet the needs of each person with migraine.

[5]. Nevertheless, migraine is an often unrecognized and under-treated disorder [6]. Only about 50% of people fulfilling the criteria for migraine had received an appropriate diagnosis and treatment [7,8]. In addition, in a nation-wide survey in Sweden only one in four of the persons diagnosed with migraine had consulted a healthcare expert and 60% of those who had were not satisfied with the information or treatment that they had been offered in the consultations [9]. Brandes [10] suggests that physicians who understand the impact of migraine on their patients’ lives are better equipped to assist with managing migraines and to help their patients to regain control of their lives. Life with migraine is a burden as it is associated with high levels of headache-related disability [11] which is affected by the worry about future attacks and a lack of control over the illness [10]. This state of uncertainty impacts upon the ability to make plans and to engage in activities [12,13]. Furthermore, the burden of being afflicted with migraine extends to the family, social relationships and work, which also affects the quality of life [9,13–15].

Persons with migraine manage their illness in a highly individual way and predominantly, use the traditional medical system, generally taking the form of prescription drugs [16]. The way they choose to manage their migraine was impacted by their own perceptions of their disability and even though those afflicted with migraine perceived it to be a serious problem, they viewed their illness as a less serious health issue than

some others have to face [17]. Peters et al. [18] have elaborated on the process of the decision-making migraine sufferers go through, a process which developed over time and operated on a justification and consequence system. With the aim of exploring the concept of vigilance, Meyer [19] describes how, in their attempts to manage life with migraine, women were always prepared to prevent and to attempt to abort attacks. Although gaining a perspective of the management of the illness is important, it only gives us an insight into one aspect of what it means to live with migraine.

Two focus group studies [20,21] found that migraine has a negative affect on the quality of life of the person afflicted and on the person's family life, work and relationships. Furthermore, Ruiz de Velasco [20] pointed out that the psychological wellbeing of the migraine sufferer is frequently affected. Moloney et al. [22] concluded that, in midlife, women experienced migraine as a continuing presence in their life and that having migraine affected their relationships and their ability to manage their responsibilities. This knowledge give an insight into how migraine can influence different aspects of life, but, however, questions still remain to be answered about what it really means to be a person living with migraine. Both Peters et al. [17] and Moloney [22] state that more qualitative research is needed about the experience of migraine to help healthcare providers develop a deeper understanding of the experience their patients are undergoing. Thus, with the intention of increasing the understanding of migraine, the aim of this study was to explore the meaning of living with migraine.

Methods

Design

Phenomenological research is characterized by beginning in the life world and, according, to Dowling [23] it tries to distinguish the nature or essence of a phenomenon to better understand what the particular experience is like. This corresponded well with the aim of our study. A hermeneutic phenomenological method, as described by van Manen [24], was chosen to explore the meaning of living with migraine. To gain understanding of the meaning of a phenomenon it is necessary to reflect on the lived experience and, as van Manen ([24] p. 32) declared, "A true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance." According to van Manen [24], the term essence is a description of a phenomenon, where the structure of lived experience is revealed in such a way that it is possible to grasp the nature and significance of the experience in a hitherto unseen way. Phenomenology also involves balancing the research context by considering the parts and the whole. Van Manen [24] argues that the ideas behind hermeneutic phenomenology acknowledge the interpretation of lived experience and believes that it is not possible to suspend or bracket pre-understandings or assumptions; rather they must be made explicit and therefore we made an effort to keep an open mind about the phenomenon and towards the participants during the study.

Participants

The Swedish Migraine Association agreed to forward information about the study to members living in county of Norrbotten, Sweden. To be included in the study the participants had to be at least 18 years old, diagnosed with migraine and speak Swedish. Letters describing the purpose of the study were sent to all members (24 persons), and a prepaid envelope was included to be used for the reply. Eleven women and one man answered, saying that they would be interested in participating in the study. Two of those people were excluded from the study; one had recently moved to the south of Sweden and one had not been diagnosed as having migraine.

Ten women participated in the study; they were aged between 37 and 69 years old. They subjectively estimated the impact migraine had on their life using one of three grades, slight, medium or severe; of the 10 women, 4 classified the impact as medium and 6 classified as it as being severe. For eight participants, the migraine had either started in their late teens or in their early twenties. For two of the women, the migraine had started when they began menopause. The number of migraine attacks varied, 1–2 attacks per year for two women, 1–4 attacks per month for 6 women and 10–20 attacks per month for two women. Four women were working full-time, four part-time and, two had retired. Eight women lived with their husbands and two women maintained separate homes from their partners. Four women had children living at home and five had adult children who no longer lived at home.

Data collection

The persons interested in participating were contacted by phone and additional information about the study was given. They all gave their written informed consent to participate in the study and the time and place of the interview was decided. Seven interviews took place at the home of the participant, and three interviews were conducted at the university, all in an undisturbed room. The interviews were performed by the first author. To capture the participant's experience of living with migraine, the interview started with the request: "Please tell me about your experience of living with migraine." The interview was supported by questions like "How did you feel then?" and "Can you tell me more about...?"

An interview is limited by the participant's openness, perceptiveness and ability to recall the memory of the situation, in addition to the ability to verbalize his or her experience [25]. As pictures can be seen as a language of a nonverbal kind [24] and as Leitch [26] claims that pictures can give knowledge beyond the limitation of language, we chose to use drawings to facilitate the interview. When the interview reached the point where the participant did not have any more information to add to the narrative, the woman was asked to draw a picture of what it is like having to live with migraine (Figure 1). Thereafter the interview continued with narrations about the picture starting with the questions: "what is in the picture?" and "what feelings and associations do you get when you look at the picture?" Two of the participants chose not to draw a picture, one of them talked instead about a film to illustrate the picture she would have drawn. The interviews lasted for an average of two and a half hours, were tape-recorded and



Figure 1. An example of a picture drawn during the interview by one participant.

transcribed verbatim with indications of nonverbal pauses, sighs, gesticulation, laughs and weeping.

Data analysis

The analyzing procedure, followed in this research, inspired by van Manen [24] involved interrelated phases; seeking meaning, theme analysis and interpretation with reflection, that considers the parts and the whole in the text. The search for meaning started with a holistic reading, which consisted of repeatedly listening, reading and re-reading the recorded and transcribed data to capture the fundamental meaning of living with migraine. Once complete, we formulated phrases that expressed the meaning. In the selective reading, the entire text was reread and phrases and sentence clusters that seemed to be thematic were marked as meaning units. As part of this selective approach, we asked: What does this unit reveal (thematically) about the phenomenon? In the detailed reading, in contrast, the preliminary themes constructed during the selective reading were controlled by asking: "What does this really reveal about the nature of living with migraine?" to add nuance and deepen the understanding of the themes. Meaning units

were considered and the themes were reread, combined and reduced, written and re-written and constantly compared to the transcribed interviews until a preliminary structure of main themes and sub-themes was identified. The preliminary themes were discussed with colleagues with experience of working with qualitative methods, including hermeneutical phenomenology. In addition, some of these colleagues live with migraine. During the process of analyzing and reflective writing, our understanding evolved and the essence was captured.

Justification of the study

The quality of phenomenological research could be strengthened by, clarifying how the principles of phenomenological philosophy are implemented in the study [27]. In our study, we adopted van Manen's ([24] p. 12) way of explaining hermeneutic phenomenological research as "a search for the fullness of living," which was understood as: the different ways a woman with migraine can possibly experience the world as a woman with migraine, and what it means to be a woman living with migraine. According to van Manen [24], phenomenological research starts with curiosity over the meaning of a

phenomenon, and researchers need to overcome private feelings and preferences to enable them to strip away scientific conceptions and thereby come to terms with a phenomenon. Therefore, as researchers, we focused on the phenomenon, formulated a phenomenological question driven by a sincere curiosity. Drew [28] emphasize that by keeping the contact with ones own intention to the phenomenon and by keeping a constant reflexion to identify and explain ones unique experience of the phenomenon, validates the study. In this article, we tried to explicate and come to terms with our pre-understanding by engaging in open and reflective discussions when exploring the women's experience of migraine. Furthermore by discussing the preliminary themes with colleges, we also were challenged about our pre-understandings as our collective understanding of the phenomenon "the meaning of living with migraine" evolved. To ensure that the interpretation we have made is possible and trustworthy, the findings are presented with quotations from the participants [29]

Ethical considerations

Participation was voluntary and the women were informed that they could change their mind about participating at any time without having to provide an explanation. The women gave their informed consent to their participation, and confidentiality was assured. The Regional Ethical Review Board in Umeå, Umeå University approved the study (Dnr 08-182M).

Findings

The analysis revealed an essence, three main themes and six sub-themes, which explored the meaning of living with migraine (Table I).

Being besieged by an attack

Having a migraine attack meant being besieged by pain and other symptoms, thereby making it impossible to function as normal. It also meant a temporary lose of both time and of power over life. The analysis revealed two sub-themes: "Being temporarily incapacitated" and "Feeling involuntarily isolated from life."

Being temporarily incapacitated

The women could be overwhelmed by a migraine attack that came out of nowhere. An attack influenced the whole body,

and produced the feeling that the body was not functioning properly. The headache was incapacitating and was hard to endure, even if it could vary in intensity. Nausea and vomiting enhanced the feeling of being really ill, and sometimes the nausea experienced was worse than the pain itself. The feeling of being incapacitated also derived from visual impairment, communication problems and increased light and noise sensitivity, the latter being described as being magnified to the extent that exposure to light and sound became really painful. This made it impossible to function in certain environments, and could last for hours after the end of a migraine attack.

"The pain is terrible, it's terrible when your are having an attack, it is horrible, you think you will..., well, you just want to fade away so you do not have to feel it, [you would] if it were possible, but you can't."

The incapacity that a migraine attack imposed, led women into more vulnerable situations. Losing the ability to communicate, to see or to function in a normal manner, made women insecure about their capacity to take care of themselves or of others who depended on them, for example, their own child, which sometimes caused fear and anxiety. Women felt that they were recurrently unable to fulfil obligations or perform their best at work, because of migraine attacks and that this put them in a weak position when it came to their opportunities to build a career for themselves or to undertake a career change. Experiencing communication problems, such as not being able to organize thoughts or using the wrong words, as well as not being able to pronounce words because the tongue became numb, was embarrassing and added to the feeling of being vulnerable.

"It [migraine] affects the whole head. It affects memory. If I'm sitting and talking to people, like when I have guests, and I feel that I'm starting to get a migraine, I think "What did they say now?" I do not remember. It is like I can not take it in."

Feeling involuntarily isolated from life

Having a migraine attack meant an inability to fully participate in life, while everyone and everything else was carrying on as usual. Women sometimes needed to spend hours in bed, which left them feeling like their life was standing still, and this created anxiety, distress and anger. Even if a migraine attack did not always lead to bed-rest, the women felt abstracted because of their reduced capacity to concentrate and to stay focused on things and people in their immediate surroundings during a migraine attack. When migraine attacks occurred during weekends, it was more burdensome for some women, because weekends normally offered the opportunity to rest and spend time with family and friends.

"You lose your life for a moment... In some ways it is like turning off the water tap and leaving life outside for the moment... to enable you go inside yourself and take care of the headache. It is important for others to know how damned limited and locked up you get."

The involuntary isolation from life extended beyond the attack itself as having to live with uncertainty about being able to fulfil things led to a reluctance to plan ahead and to

Table I. Overview of the essence, main themes, and sub-themes of the phenomenon.

Essence	Being obliged to endure a life accompanied by an unpredictable and invisible disorder
Main theme	<i>Being besieged by an attack</i>
Sub-theme	Being temporarily incapacitated
Sub-theme	Feeling involuntarily isolated from life
Main theme	<i>Struggling in a life characterized by uncertainty</i>
Sub-theme	Being in a state of constant readiness
Sub-theme	Worrying about the use of medication
Main theme	<i>Living with an invisible disorder</i>
Sub-theme	Living with the fear of not being believed
Sub-theme	Struggling to avoid being doubted

have dreams for the future, such as going travelling or having a party. As a woman said, “I would never ever plan my own wedding; imagine if I couldn’t attend because of a migraine.” Recurrently needing to cancel activities and thereby, possibly, spoil things for others was experienced as being harder than the symptoms themselves, which led to less desire to do things and fewer social contacts.

“The worry about having a migraine attack takes away the joy of planning something joyful. You think “This is going to be fun!” but then you think I might get a migraine. I have probably never felt real joy because of always having this in the back of my mind; it is always present.”

Struggling in a life characterized by uncertainty

As migraine is unpredictable, women were challenged by both trying to increase their own control and by adjusting their lives to the uncertainty, which led to having to live their lives in state of constant readiness. Women experienced relief from using medication, but worried about the long-term health implications and lacked satisfactory alternative treatments. The analysis revealed two sub-themes “Living in a constant state of readiness” and “Worrying about the use of medication.”

Living in a constant state of readiness

The women never lost hope that the migraine would disappear at some time in the future, and in the meantime they tried to cope with the uncertainty. Learning to live with migraine was a process of adjusting, which meant constantly being on guard and always considering what would happen if they had a migraine before committing themselves to engage in activities. The adjustment process included trying to even out the demands that life made on them and their time and energy by, striving to balance the demands of life.

Living with migraine meant having the feeling of not being in control, and the women struggled to increase their sense of control over their illness. The notion of control did not only involve being able to make plans and realize them, but also restrictions on the activities undertaken and food eaten because of the fear of triggering a migraine. Sometimes the women felt that they were controlled by the migraine, which was described by one woman with a metaphor, “It’s as though I am forced to live with somebody who always interrupts and decides what I should or should not do.” Living life in a constant state of readiness meant always searching for and trying to avoid anything that would trigger a migraine to gain control over them. However, the participants’ sensitivity varied, so potential triggers might prove unproblematic on one occasion, but then subsequent exposure might then trigger a migraine, which aggravated the possibility to gain control over the triggers. As stress was a common trigger, women tried to both control it, through exercise, relaxation and mental training and to adjust their lives to avoid stressful situations. Being in a constant state of readiness meant, however, that limitations were inevitably imposed on life owing to the adjustments made. The adjustments included aspects like always needing to sleep at a given time, and making restrictions on what to eat and drink, which sometimes left the women feeling lonely

and different from others, as well as sad over how their life had turned out.

“You learn to live with it and you do not know what life would be without it, but it is like permanently wearing a backpack, which is tough, you must always consider the possibility not being able to do things.”

Worrying about the use of medication

Women had tested different treatments for migraine and experienced different outcomes, but nevertheless they considered prescribed medication to be the key to preventing or stopping their migraine attacks. On most occasions, medication provided relief and made life bearable during a migraine. Nonetheless, using medication was never an easy solution as it raised fears about the negative affect long-term use would have on the body and it was associated with insecurity about the risk of becoming addicted. Furthermore, the use of medication could not restore full function; on the contrary, it was associated with feeling dizzy, tired and having a decreased ability to concentrate. The women’s misgivings about taking medication made them hesitate and negotiate with themselves before taking medication, but in the end they often felt that they had no alternative; “... taking medicine all your life! How sort of solution is that? But I do not have a choice because otherwise I would feel so bad I would not be able to live at all.” Having well-functioning medicine available for use increased the feeling of control over migraine and served as a preventative against the most severe migraine symptoms, but it also caused worry, about forgetting to always have the medicine to hand. Thereby medication could be said to ease the burden in some ways, but it added to the consequences of living a life in uncertainty.

“Thanks to the new medication, I can handle it [the migraines] now... I do not panic about getting migraine, so in that way I have gained a new life, because I had a feeling of panic as migraine is so awful, that you get handicapped by it.”

Living with an invisible disorder

Central to all of the women’s narratives was that migraine was an invisible disorder, and that the women were often doubted and had a deep desire to be believed. The women struggled to hide their symptoms and pushed themselves to avoid being doubted. The analysis revealed two sub-themes, “Living with fear of not being believed” and “Struggling to avoid being doubted.”

Living with the fear of not being believed

The feeling of not being believed was one of the most burdensome aspects of living with migraine and this led to feelings of shame about being afflicted by migraine. The women’s experiences of not being understood referred mostly to the invisibility of migraine and the fact that no one else can see or experience how painful and dreadful it is. The women narrated that migraine was perceived as being the same as a headache by society and, therefore, that many people interpreted a migraine as being an insignificant problem. This meant that migraine was not perceived to be an acceptable excuse for not being able to participate in social commitments or perform

duties. The sense of not being believed made the women feel that their willingness to do things and to participate in social activities was being brought into question, and because of this, they feared being perceived as either a weak or a lazy person. Moreover, the women worried that their colleagues would think that they were feigning illness if they had to be on sick leave for a day.

“People can believe that it [migraine] is an excuse for not going somewhere, it is stupid not to say [that you have migraine], but it is like you feel ashamed sometimes... you do not want people to think you are a wimp.”

A sense of not being believed could also occur when meeting professionals in the healthcare services. Occasionally, they were met with negligence, which led to the feeling that they were not being taken seriously. However, when feeling that their problem was being acknowledged, a sense of security occurred among the women. When the women encountered staff in the health service without a great deal of knowledge of migraine, their lack of understanding contributed to feeling that it was not worth searching healthcare other than to renew prescriptions.

Struggling to avoid being doubted

To avoid being doubted the women pushed themselves to continue working despite having a migraine attack. They also tried to keep ahead of their workload in case they became sick later on during the week. During severe attacks, the women had no choice but to stay at home and, between attacks, they tried to live a normal healthy life, undertaking the same workload as any person without migraine. The threat of being doubted made the women unwilling to tell those in their surroundings about their migraine, and they tried to hide the symptoms. This meant that the perpetual worry, the limitations inflicted by migraine on their life to avoid migraine also remained invisible to others. In contrast, however, when others revealed their confidence, it resulted in a feeling that there was less pressure to hide symptoms and it enabled the participant to take the time to recover, which in turn led to less migraine attacks.

“Two years ago I ended up in the hospital. It was impossible to go on. Hopefully one learns from [an experience like] this. I believe that with increased confidence from [colleagues at] work, one dares to stay at home and rest. At the beginning I just went on... and then the migraine got ten times worse.”

Essence: Being obliged to endure a life accompanied by an unpredictable and invisible disorder

Migraine permanently accompanied the women through life, whether by means of its presence or in the form of a perpetual threat that needed to be taken into account. It was characterized by its invisibility and its unpredictability. Migraine could strike hard without any notice, and was incapacitating to the extent that the woman had to slow down her life, or even put it on hold for the moment. The women were obliged to make adjustments and fought a never-ending struggle to control and avoid their migraine, as well as to endure the attacks.

The women also struggled to maintain their activities when inflicted by a migraine, partly out of fear of losing the confidence of others who might not believe that migraine was a genuinely debilitating illness.

Discussion

This study was intended to explore the meaning of living with migraine. The essential meaning of living with migraine was understood as “Being obliged to endure a life accompanied by an unpredictable and invisible disorder.” This indicates that living with migraine means having to endure life with a disorder that is not a constant source of pain, but which directs and rules one’s life, owing to the perpetual threat of that one will become incapacitated. The invisibility of the disorder and the feeling of being doubted about whether one was really being afflicted with migraine further complicates life. The knowledge provided by the research presented here adds a new perspective revealing the deep meaning of living with migraine, and it can be seen as a complement to existing research, which has pointed out the impact migraine has on life [20–22] as well as on the strategies adopted to manage it [16–19].

The women struggled with a life of uncertainty, not knowing when the attacks would strike and lived with fear of not being able to take care of themselves or of their dependents during an attack. The unpredictability of migraine resulted in the need for the women to anticipate and be prepared for an eventual attack of migraine, as a result of which, they could never let their guard down. This could be understood to be a strategy used by the women to cope with their migraine, and it mirrors the findings of Meyer [19], who described vigilance in women with migraine as “the art of watching out,” and explained that women scanned the environment, both internally and externally for changes or possible indications of change.

In this research, the meaning of having a migraine attack was understood as being besieged by an attack. This differentiates our study from earlier ones that offered descriptions of the symptoms [17,20,22]. The meaning of being besieged arose because the body was temporarily dominated by the symptoms of the migraine attack, which made it impossible to function and fully participate in life and forced the women to put aside everything else to deal with their migraine. Medication could alleviate the symptoms, but the women did not fully recover until the attack was over, and, on an ongoing basis, they still were preoccupied with the potential threat of migraine and with the measures required to avoid it.

The use of medication both eased and compounded the consequences of living in a state of uncertainty. It contributed to the feeling of having some control over life, but it also caused worries about the long-term consequences of taking medication and the risk of becoming addicted. This made women negotiate with themselves before taking medicine. This could be understood in the light of Meyer’s [19] and Peters et al. [18] research, where people with migraine calculated the risk of taking medication to determine whether the benefits of the treatment outweighed the consequences. The women in our study felt that they did not actually have a choice other than to take medication, something that the women in Meyer’s

study [19] did not express explicitly, however when it came to situations when they needed to be able to function, they took migraine medicine as first choice.

Living with migraine meant having to live with an invisible disorder, which influenced the women's experience of not being believed. This is in line with research conducted by Soderberg et al. [30], who described how invisible symptoms associated with fibromyalgia also led to the feeling of not being believed by others. In our study, the feeling of being doubted came to the fore when those in the woman's immediate surroundings viewed migraine as an insignificant problem, more like an ordinary headache. The women stated that the invisibility of pain was the main reason for them not being believed. Holloway [31] described how the very invisibility of pain caused persons with chronic lower back pain problems of being discredited. Some symptoms of migraine may, however, have the reverse effect, such as that described by Moloney et al. [22], who said that the visibility of vomiting as a symptom validated the seriousness of the headache to others.

It might seem paradoxical that the women in this study wished for more understanding at the same time as they tried to keep others from knowing about their disease, however, this could be understood as a struggle between the benefits of being understood and the fear of not being believed. The importance of being understood emerges in Olsson's et al. [32] research, where women with multiple sclerosis revealed that feeling understood was central to feeling well despite their illness. Furthermore, the participants in an investigation by Lun et al. [33] reported higher life satisfaction and fewer physical symptoms on days when they felt understood by others. When the women in our study felt trusted, they did not need to hide their symptoms and could take the time required to recover, which led to a decrease in the number of migraine attacks. However, to our knowledge, this has not been shown in migraine research previously and more research is needed about the importance of being understood when living with migraine.

Experience of being doubted was, however, a burdensome aspect of living with migraine and this was in line with Cottrell et al. [21], where misunderstanding by others was highlighted as being an area people with migraine found most difficult to live with. The women in our study experienced guilt about having migraine as a result of others' perceptions that migraine was an excuse to avoid responsibilities, and Moloney et al. [22] referred to women's feeling of guilt because of the stigma that migraine could be avoided if the women exerted sufficient self-discipline. The women in our study struggled to fulfil their obligations and not cancel things when they had a migraine attack to avoid being doubted. This could be understood as an avoidance of stigmatization in accordance with Holloway [31], who described how avoidance of stigmatization may lead either to risk behaviours that might exacerbate pain, or to concealment and social isolation. Owing to the uncertainty of having a migraine attack, the women in our study sometimes refused invitations and social engagements, which could lead to social isolation, a finding that emerged in a study by Ruiz de Velasco et al. [20], where persons with migraine lost contacts with their friends and reported varying

degrees of social isolation. It is possible that hiding migraine symptoms, as the women stated they did, might lead to them not seeking social support, which was apparent in the research of Gunel and Akkaya [34], where people with migraine used social support less than a group without migraine. In addition to not seeking help, Moloney et al. [22] argued that the existing stigma of migraine decreases the likelihood of a person with migraine being able to obtain appropriate treatment and social support.

Women in this study lived with the fear of not being believed and, when meeting healthcare professionals, they had experienced both that their illness was acknowledged and that they were not being taken seriously. According to Ramsey [35], some relief can be provided when women with migraine are recognized as truly suffering. In addition, Buse et al. [6] argued that the care of persons with migraine can improve when healthcare providers have an increased understanding of and communicate about the burden of migraine. Our study increases knowledge of the meaning of living with migraine and improves the understanding of what life with migraine can be like.

Methodological considerations

This research relied on the narrative accounts of ten women and on their reflections to provide an understanding of the phenomenon from the inside, from the participants' perspective [24]. One limitation might be that it was only women who were represented, and therefore we do not know if the findings would have been different if men were to have participated. Another limitation is that all of the women were members of the Swedish Migraine Association, and therefore it is possible that they were more active in handling their migraine than the average person with migraine. However, they all stated that the only engagement they had in the association was reading the magazine.

The collected data contained rich information and was, therefore, judged to be adequate to meet the aims of this study. According to Norlyk and Harder [27], the sampling criteria in phenomenological research should be people with experience of the phenomenon under consideration and that the variation within the phenomenological framework reflects variation in the experiences of the participants. The interviews were about two and a half hours long, which indicates the richness of the experience of living with migraine. The drawing of the picture was performed when the woman felt that she had no more to add to her narrative, which mostly occurred one to one and a half hours into the interview. The women were promised that, if they were prepared to attempt to make a drawing of what it is like having to live with migraine, then their pictures would be neither reproduced, nor displayed, without their permission. This resulted in all of the women but two drawing an image. The use of the pictures enriched the discussions and we can report that valuable additional information was obtained directly through their use. This is in accordance with the findings of Guillemin [36], who concluded that drawing pictures is a process of knowledge production about the illness itself and that it offers further insight into how people understand their

illness. Guillemín [36] also argued that when the participants make their own interpretation of their drawing, it further validates the drawing as a research method and it can be used together with other methods of data collection, for example interviews. After concluding the analysis and the writing process, we asked one of the women for her consent to reproduce her drawing in the article. This drawing is to be seen as an example, as all the drawings were different from each other, as they reflect each woman's unique experiences.

Conclusions

The findings show that living with migraine means living life in a state of uncertainty, being engaged in a constant struggle to maintain control, and living with the fear of not being believed. Having a migraine attack is more than having a headache; it means that one is temporarily besieged by pain and other symptoms, which makes it impossible to function normally. The treatment of migraine must involve more than just treating the symptoms; thus, it is important to explore and acknowledge what it means to live with migraine, to ensure that those afflicted will encounter greater understanding.

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Paper II

EMPIRICAL STUDIES

Travelling along a road with obstacles: Experiences of managing life to feel well while living with migraine

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Abstract

Living a life with migraine can impair one's sense of feeling well, and migraine is a disorder that is associated with substantial disability. Earlier research on how people manage their migraine has given important insight into these people's preventive actions and how they handle their attacks, but there is still a lack of knowledge of how persons with migraine manage their lives to feel well from a more holistic viewpoint. Therefore, the aim of this study was to explore lived experiences of managing life to feel well while living with migraine. Nineteen persons with migraine were interviewed. A hermeneutic-phenomenological approach was used to explore their lived experiences. The findings reveal that persons with migraine not only used preventive strategies to abort and ease the consequences of migraine but also tried to amplify the good in life through increasing their energy and joy and through reaching peace with being afflicted with migraine. The findings of this study can encourage healthcare providers, as well as persons with migraine, to consider channeling their efforts into strategies aiming to amplify the good in life, including reaching peace of mind despite being afflicted.

Key words: *Hermeneutic-phenomenology, headache management, lived experiences, patient perspective, health promotion, well-being*

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Living with migraine means having recurrent painful headaches, often associated with symptoms such as nausea, photophobia, or phonophobia (Blumenfeld et al. 2011). However, the periods between the attacks are not symptom-free, and quite often the person with migraine experiences fear or worry about the next attack (Wacogne, Lacoste, Guillibert, Hugues, & Le Jeune, 2003). Thus, his or her life could revolve around maintaining readiness for an attack and making arrangements to avoid triggering migraine (Rutberg & Öhrling, 2012).

Migraine is a chronic disorder that is associated with substantial disability (Leonardi, Raggi, Ajovalasit, Bussone, & D'Amico, 2010), so living with migraine can impair the quality of life (Brandes, 2008). To improve their health, persons with migraine actively involve themselves in the management of their disorder (Peters, Abu-Saad, Vydellingum, Dowson & Murphy, 2003). While researching the ways that persons with migraine manage their

disorder, Peters, Abu-Saad, Vydellingum, Dowson, and Murphy (2004) discovered that these people rely on a problem-focused management that comprises seeking information and support and taking problem-solving actions. In a previous study, Peters et al. (2003) also found that people with migraine operated on the basis of a justification and consequence system, for both acute and preventive management of migraine. Moreover, both Moloney, Strickland, DeRossett, Melby, and Dietrich (2006) and Meyer (2002) concluded that the women they interviewed were always prepared to prevent and control their migraine. The research thus far on managing migraine gives important insight into how persons with migraine try to control and abort their migraine attacks; however, there is still a lack of knowledge of how persons with migraine manage their lives to feel well in addition to taking preventive measures. Thus, we agree with Anand and Sharma (2007) that more qualitative research is needed about

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the management of migraine from the patients' perspective because such research could provide important information for doctors and other health-care professionals, and possibly help practitioners to develop future care and education.

Good health is more than only the absence of disease or weakness. In 1947, the World Health Organization defined good health as a state of complete physical, psychological, and social well-being. There is no generally accepted definition of well-being, even though it is often used synonymously with good health (Svensson & Hallberg, 2011). According to Lehnert, Sudeck, and Conzelmann (2012), subjective well-being consists of psychological well-being, both cognitive and affective; somatic well-being, both physical self-evaluations and physical functioning; and social well-being. We agree with the view that the concept of well-being rests on an implicit view of what it means to be a whole and healthy human being, and that it is important to strive to look at the whole picture of how persons with migraine manage their lives to feel well (Sarvimäki, 2006). Therefore, the aim of this study is to explore lived experiences of managing life to feel well while living with migraine.

Methodological framework

The lifeworld is the world that we all participate in and are a part of, and it is as well the world of lived experience (Husserl, 1970). The framework of this study is the lifeworld, as it is through the lived experiences that researchers, using a hermeneutic-phenomenological approach, search for knowledge. To understand the meaning of a phenomenon, we need to interpret the lived experience of the phenomenon, and according to van Manen (1997), phenomenology means understanding being in the lifeworld. In this study, we are interested in knowing more about how it is to be in the world as a person living with migraine and managing life to feel well.

According to Gadamer (1994), the human being can only understand the world on the basis of earlier experiences, theories, or philosophies. He further argues that researchers try to fuse their horizon of understanding with the horizon provided by participant in studies or by text to increase knowledge. Agreeing with Gadamer (1994) and van Manen (1997) that it is not possible to suspend or bracket one's preunderstanding and beliefs, the present authors have tried to make them explicit, in order to meet the phenomenon in a way that is as free and unprejudiced as possible. None of the present authors has experience of living with migraine or other chronic disorders. However, that does not free us from presumptions of what it means to manage life to

feel well while living with migraine. Previously, we conducted a study of the meaning of living with migraine (Rutberg & Öhrling, 2012), and we have worked clinically (SR as a physical therapist, KÖ as a nurse, and CK as a health consultant) and met people with chronic disorders trying to improve their health.

Method

Participants and procedure

Seventeen women and two men diagnosed with migraine participated in the study. The criteria for participation were a minimum age of 18 years, living with migraine and the ability to speak Swedish. The participants' age ranged from 20 to 69 years (md: 48 years), and 17 persons had been experiencing their symptoms for about 9–59 years, while two persons had had their symptoms and diagnosis for about 1 year or less. The number of migraine attacks varied: three participants experienced 1–8 attacks per year, 10 participants experienced 1–4 attacks per month, four experienced 5–8 attacks per month, and two experienced 12–25 attacks per month. Eleven persons were working or studying full-time, and three persons were working or studying part-time due to migraine. Four persons were pensioners, and one was receiving a disability pension.

The participation in the study was arranged through the Swedish Migraine Association, as well as through physical therapists at primary-care clinics in the northern part of Sweden. The Swedish Migraine Association forwarded letters describing the purpose of the study to all its members in the northern part of Sweden. Eight persons answered, saying that they would be interested in participating in the study. The physical therapists at the primary-care clinics were contacted by phone and asked if they were presently treating any persons diagnosed with migraine. At nine of those clinics, the physical therapists were treating at least one person with migraine. We sent information about the study to the physical therapists at each clinic, and they passed the information to their patient(s). The persons interested in participating were contacted by phone, and additional information about the study was given and the time and place of an interview were decided. Twelve interviews took place at the home or workplace of the participant, and seven interviews were conducted at different campuses at the Luleå University of Technology, all of them held in an undisturbed room.

Data collection

This study is built on in-depth interviews with a narrative approach. The interviews were conducted

by the first author and digitally recorded. A pilot interview was performed to test the research questions; then, minor revisions were made. The participants were asked to talk about their experiences of managing their life with migraine and what they did to feel well. To encourage the participants to elaborate upon their experiences, the interviewer asked questions like, “How did you feel then?” and “Can you tell me more about ...?” The interviews lasted between 35 and 135 minutes each and were transcribed verbatim.

Data analysis

To transform personal meanings and experiences from interview text into understanding, we chose to use a hermeneutic-phenomenological approach inspired by van Manen (1997). The analysis was guided by two overarching questions: “What makes this lived experience what it is?” and “What is unique about this experience?” (van Manen, 1997). Hermeneutic-phenomenological research follows interrelated phases of seeking meaning, theme analysis, and interpretation with reflection activities that are performed in a movement back and forth to reach understanding of the phenomenon (van Manen, 1997).

Each interview was read and reread to capture the main significance of the interview as a whole, inspired by van Manens (1997) “wholistic approach” (p. 93). Aspects or qualities of the phenomenon were written down as essential themes. To find the characteristics of the essential themes, the interviews were read again line-by-line, and statements or phrases that seemed to reveal aspects of lived experience of managing life to feel well were highlighted. van Manen (1997) refers this process to a selective and detailed approach. To do justice to the fullness and ambiguity of the participants’ experiences of managing life with migraine, we involved ourselves in a process of writing and rewriting. van Manen (1997) argues that rewriting is a complex process of rethinking, reflecting, and recognizing; he explains, “writing teaches us what we know and in what way we know what we know” (p. 127). Therefore, writing is a way to exercise self-consciousness. We discussed the essential themes and their characteristics throughout the analysis process and then presented our findings as a whole through two overarching themes and four subthemes.

The process of making our preunderstanding, assumptions, and beliefs as explicit as possible started early with discussions about our perceptions of well-being, migraine, and managing life to feel well, and we kept a record of our preunderstanding. Inspired by Drew (2001), we tried to explore our

preunderstanding by writing personal statements about the highlighted phrases that we had chosen to reveal aspects of managing life to feel well. We then attempted to find the questions that the personal statements potentially answered, to become aware of our preunderstandings and what we were overlooking. To challenge further our understanding of the preliminary findings, we discussed them with researchers who were highly experienced in qualitative research methods and healthcare.

Ethical considerations

The Regional Ethical Review Board at Umeå in Sweden gave their approval of this study (Ref. no. 08–182M). The persons included in the study gave their informed consent to participate after full confidentiality was assured and after they received information that they could change their mind about participating at any time without providing any explanation.

Findings

The analysis revealed two main themes and four subthemes, which capture the experiences of managing life to feel well while living with migraine (Table I).

Building a foundation of safeness

To feel well while living with migraine, it was necessary to try to avert the threat of having a migraine attack, as well as to possess potent methods of alleviating the attacks. The persons used their experiences of triggers as a guide, to increase their sense of control over migraine. Their experiences of migraine attacks influenced their way of managing triggers. Being able to alleviate the attacks induced a sense of safeness and gave them a sense of increased power, enabling them to take control of their lives. This feeling of safeness made it possible for them to experiment with triggers and to explore new possibilities of feeling well. Being attentive to their migraine increased their knowledge and helped them to build a foundation of safeness.

Table I. Overview of the main themes and subthemes.

Main theme	Building a foundation of safeness
Subtheme	Using experiences of triggers as a guide
Subtheme	Striving for power to be in control
Main theme	Amplifying the good in life
Subtheme	Acting thoughtfully to increase one’s energy and joy
Subtheme	Being in a process of accepting migraine as a part of life

Using experiences of triggers as a guide. To reduce the risk of having a migraine attack, the persons with migraine constantly searched for and had become aware of triggers. In their search for triggers, they also considered other people's experiences of triggers through sharing them in conversations or by reading about them in magazines. It was important to take all the triggers into consideration, as it was sometimes possible to expose oneself to one trigger, but not to a combination of several triggers. In addition, the persons with migraine experienced different degrees of sensitivity to triggers. They furthermore experienced that their personal energy levels affected their sensitivity, so they considered it important not to let their level of energy decrease, in order to avoid triggering migraine. These experiences had led them to eat at regular times, to cherish a good night's sleep, and to carry out activities that increased their energy.

I know I need to sleep to have the energy . . . I like to take a glass of red wine or a drink, but I know that in combination with stress and other things, it is easier for me to get a migraine; then you learn to balance; if you have had a stressful week or slept badly or other things in life that affect you, then you do not drink a glass of wine on a Friday evening.

Their earlier experiences had taught them how to manage and acquire an awareness of their triggers. The triggers were experienced as being of a varied nature. Some of the triggers of migraine lay beyond the person's control, such as weather and hormonal changes, whereas others were more controllable in the manner that allergens are controllable, for example, triggers such as food, alcohol, and sunlight. To manage triggers, it was important always to be prepared and to appraise whether it was worthwhile exposing oneself to them or not.

. . . yes, you become a bit like that [attentive], like the sun, because when it is really bright, then you need to use sunglasses, yes, you do not need to provoke fate . . . all the time you think preventively . . .

Triggers like stress had made some of the persons with migraine plan their lives in such a way that they would avoid stress, and others had developed strategies to decrease their levels of stress, such as exercising, practicing relaxation training, and so on.

. . . the exercise really helps, it minimizes the attacks . . . if I am stressed or frustrated, it [the migraine] usually comes, or if I eat badly . . .

the exercise makes me more balanced as a person, more tolerant of stress . . .

Having pain in other body parts, especially the neck or head, increased their proneness to migraine attacks. Those who experienced such pain used exercise and stretching, and some consulted a physical therapist or some other healthcare professional to improve their health. By being attentive and listening to the signals from their bodies, the persons with migraine had found it possible to recognize early signs of triggers. This made it possible to know, for example, when it was necessary to lower their stress or to reduce the strain on the muscles in their neck and shoulders.

Striving for power to be in control. One need that people with migraine have is access to potent ways of treating the symptoms of a migraine attack so that they can function. The persons with migraine expressed how they struggled or had struggled previously to discover ways of dealing with the pain and the other symptoms of a migraine attack, and how they had panicked just at the thought of having an attack. Therefore, as long as a migraine attack meant a threat of not being able to function, it imposed an uncertainty in life, and it was vital to have a strategy for acute treatment. Having the possibility of alleviating the symptoms of an attack was a prerequisite for enhancing their sense of being in control of their own lives and, thereby, for increasing their notion of feeling well. With this security, they could make time-sensitive plans, such as holiday travel, parties, and other social events.

The medications are the thing that provides a base of safety . . . when I have an episode I can take a pill and then I do not need to live in uncertainty; it gives me the power to rule over my life . . .

To ease the symptoms of migraine, the persons talked mainly about using medication. However, they generally did not want to use more medication than was absolutely necessary, as they were afraid that long-term use could lower the effect of the medication, negatively affect them, or increase the risk of becoming addicted to the medication. This imposed the threat of losing the ability to alleviate the attacks and the power to be in control of one's life. Therefore, they often negotiated the use of medication with themselves, deliberating over what kind of treatment they needed to use and whether to start treating a migraine attack at once, or whether it was possible to wait. Sometimes the easiest way to function quickly was to take medication immediately.

Having preventive strategies could increase the feeling of control over migraine, and some persons took preventive medication or acupuncture treatment to ease their migraine. Avoiding triggers was often considered to be a good and sometimes necessary strategy to avoid migraine, but at the same time, the persons with migraine had to create a balance whereby avoidance did not diminish and limit their lives too much. By experimenting with their triggers and testing their limits, some of the interviewed persons successfully increased their sense of being in control of their own lives.

Every year I try to think of something that frightens me and I challenge myself to do it ... last year, I decided to take my dog to an exhibition myself, which does not sound so tough, but when you have migraine, you have a tenseness; I got some attacks a couple of times at these dog exhibitions, but in the end, I managed it and it has gone really well ... to me, everything is possible, and that is a really nice feeling.

Moreover, by compensating for the limitations due to avoidance with other activities or things, the sense of having the power to rule one's life could be enhanced. However, persons who did not have potent ways of treating their migraine attacks had a greater need to focus on avoiding triggers. Being in that kind of situation meant that thoughts of migraine occupied a large space in their lives; it limited their activities and ruled over the choices that they could make.

... earlier, then, my energy went to trying to control so that you wouldn't get a migraine; yes everything, all your power went to these things; you did not do anything else ... today, I look for things to make me feel better ...

Amplifying the good in life

When the persons in the study experienced a high sense of well-being, they felt increased tolerance of migraine attacks. To increase their well-being, they tried to amplify the good in life by making thoughtful choices. When they had reached a sense of peace through acceptance of the fact that migraine was a part of life, this served as a plateau from which they could find more ways of amplifying the good in life.

Acting thoughtfully to increase one's energy and joy. The persons with migraine general sense of well-being affected both the quantity and the severity of their migraine attacks, as well as their ability to handle the concurrent pain and other symptoms. With an

increased sense of well-being, migraine attacks were easier to bear, and the number of migraine attacks sometimes could decrease. Conversely, when they were suffering from depressions or facing crises in life, such as a divorce, an attack could be harder to tolerate, and the number of migraine attack could escalate. The persons pursued activities that strengthened their sense of energy and well-being to increase their resistance to migraine. Exercising was a common way to increase one's sense of well-being. In addition to decreasing muscle tensions, lowering stress, and leaving a pleasant feeling in one's body, it instilled the feeling of being capable and having physical strength.

You need to find these things [things that give energy], otherwise it is as if you just bury yourself in thoughts of, 'I can't do this, then I get pain,' and then you feel really bad; then you do not find any sunshine in your life ... having high energy and feeling well makes me not get so ill ...

The persons with migraine made an effort to use their energy and resources wisely, and they found it vital to find the things that increased their sense of health and to be aware of the things that "drained" their energy. They felt that they had become more attentive to what was best for them, such as prioritizing something that reinforced their energy after an attack, instead of hastening to do all the things that they had not managed to do during the attack.

... it [migraine] takes one's energy ... I try to enjoy myself [when I do not have migraine] and not just hurry up and clean and wash, etc.; there are always things that are postponed and not prioritized, there is always a lot to do, but you need to rest and think, 'Oh, how I feel good.'

Nevertheless, when the persons with migraine felt guilty about not being able to fulfill their commitments during an attack, they prioritized the fulfillment of commitments over feeling better. In the long run, however, pushing themselves to meet their own demands and those of others without sufficient time or energy led to them feeling run-down, which could cause them to lose the joy of doing the things that they had appreciated earlier. In contrast, when they took the time to evaluate their resources and energy and prioritized activities of their own choice in addition to obligations, they experienced a better quality of life. Moreover, the persons with migraine told about feeling more joy and self-esteem after they focused on their possibilities rather than their barriers (i.e., limitations due to migraine). Some persons had tried cognitive behavioral therapy or

mindfulness and found these approaches to be helpful. By being in the present and trying to enjoy life, they made their lives richer, and worrying about having a migraine attack did not drain as much energy as previously.

When I am healthy and do not have a headache, I think that nobody is happier than me, I really appreciate those days ... instead of going around and being bitter or in a bad mood and whining all the time, I have chosen to make the best of the situation; things are fine after all ... the days you are sick, you take things for what they are and when you are fine, things are really fine; that is my way of looking at it ...

Being in a process of accepting migraine as a part of life. Acceptance of being afflicted with migraine had different meanings among the persons with migraine. Those who felt at peace with being afflicted could look back and see that accepting the disorder had been a process of reaching a sense of calm and a security within themselves. This kind of acceptance had its roots in facing the fact that migraine was a part of life that would not go away for a long time or at all. Feeling at peace with being afflicted meant that guilt in general was not present or did not rule them as it had done before. Similarly, they expressed having reduced feelings of remorse for not having the strength and energy to handle things during an attack. Furthermore, it meant that they did not bother as much as they had previously about what everybody else thought and that they found it easier to tell others about their migraine, without being bothered by feelings of embarrassment or shame.

I think it [having acceptance] is important; earlier, I could see myself as a failure when I did not have the energy to do certain things, but now that's the way it is and you need to accept it; if you don't have the strength you don't have it ...

There were also persons with migraine who described their acceptance of the disorder as merely knowing the fact that they suffered from it, and they expressed frustration and limitations due to migraine in their life. It was difficult for them to accept the uncertainty of having attacks, and they often compared their lives to the "normal" lives of others or to the time before they were afflicted with migraine. They were more often waiting for the migraine to disappear and dreaming about what life would be like without migraine. Reaching acceptance of migraine as being a part of life and only a part, made

it easier to channel efforts into feeling well and not just trying to avert the sources of harm.

I do not have a choice [but to accept it]; it [migraine] is nothing I can opt out of, so I wait for better medications and more research to come so they can arrive at a way for me to get rid of this and so I do not need to have this worry all the time ...

Moreover, the persons' surrounding environment influenced his or her process of acceptance and feeling at peace with being afflicted. The interviewed persons' inner sense of acceptance fluctuated to some extent depending on the situation and the attitudes of the surrounding people. When the persons with migraine sensed that they were trusted and understood, they found it easier to accept their disorder and to handle the emotions aroused by being afflicted. However, when they encountered people who questioned the seriousness of their migraine and who imposed feelings of guilt when they were unable to perform their duties due to migraine, they found it more challenging to accept their situation. Close relatives and friends, as well as influential people, such as employers, healthcare personnel, and perhaps, in particular, doctors, influenced the persons' own acceptance of being afflicted with migraine, by either taking them seriously or by causing them to feel mistrusted or dismissed.

I have a good back-up, a doctor who understands: she has migraine herself and when I explain something she nods and recognizes, that is important ... I do not care a lot about what other people think, because I know and I am able and I have a great doctor who supports me ... she takes me seriously when I tell her that I am in real pain ... that migraine is a real sickness ...

Fairly often, persons with migraine were asked to explain the reasons why a migraine attack had appeared. For example, they were asked whether they had done or not done this or that, and it was easy for them to perceive such questions as implying that they themselves were responsible for the attack. Therefore, it was important for them to have explanations to give to others as to why they had suffered a migraine attack. Another help in reaching acceptance was the realization that they were neither alone nor strange, which could be achieved, for example, by reading about or meeting other people afflicted with migraine.

Many want to know, 'What have you eaten?' I have even heard, 'Perhaps you laughed too much, so

you got tense,'... I know they mean well, but there are hundreds of reasons; it is as if I am responsible, almost as if they mean, 'What have you done?'... then, I become like, 'It's none of your business!' and then I can say that the weather has changed and then there is nothing more to think about ... I have accepted, it is me ...

Discussion

The findings of the present study reveal that managing life to feel well while living with migraine means both building a foundation of safeness and amplifying the good in life. Earlier studies on how persons manage their migraine has focused on preventive strategies (Meyer, 2002; Moloney et al. 2006; Peters et al. 2003, 2004). The necessity of promoting the good in life, in addition to preventive strategies in order to feel well, is the finding of the present study that add to previous knowledge. During the analysis, the following parable was written about our understanding:

Managing life with migraine is like travelling along a road with obstacles (i.e., triggers of migraine). In order to avoid harm and to feel safe, you either avoid the obstacles or try to remove them from the road. Hitting one obstacle might be tolerable, but certainly not hitting several. The more one feels that one can handle a hit (alleviate an attacks); the smaller the obstacles on the road appear. By investing in increasing one's energy and power (i.e., increasing one's well-being), one decreases the extent to which one feels hurt by a hit. By accepting the obstacles along the road and the possibility of hitting them as a natural part of the journey, the ride becomes easier and more effort can be channeled into making it as pleasant as possible.

The present study has shown that it is crucial to build a basic foundation of safeness. A means to reach safeness was to avert the threat of migraine, and the persons in the present study talked about dealing with triggers. However, the interpretations that some triggers lower the energy levels of the person with migraine and that having decreased energy would, therefore, increase the risk of having a migraine attack are not to be found in previous literature and must, therefore, be treated with caution. Moreover, Brandes (2008) has stated that migraine affects well-being, but whether well-being affects migraine is not so evident in previous research. The findings in the present study point to increased well-being giving higher tolerance of migraine, and the persons with migraine describe how they tried to amplify the

good in life as a strategy to feel better. This is in line with Varkey, Linde, and Henoch (2012) who found that persons with migraine use strategies to enhance their well-being and that the sense of feeling well reduced the burden associated with migraine. Therefore, we argue that, in the treatment of migraine, efforts should be channeled into increasing the energy and well-being of persons with migraine to raise their migraine threshold and decrease their burden of migraine, instead of just using preventing strategies.

The persons with migraine used their experience of triggers as a guide to avoid migraine. Triggers were like obstacles on the road of life, which they sometimes were able to avoid and sometimes needed to tackle. When the avoidance restricted life, particularly with regard to social relations or physical activity, it was hard to bear. Recent research (Martin, 2010; Martin & MacLeod, 2009) has questioned the non-evidence-based, yet commonly accepted, preventive strategy of avoiding migraine triggers. Instead, they argue in favor of learning to cope with triggers as a more effective long-term strategy. In the present study, some persons with migraine had tried to challenge the limitations imposed by triggers and found that this enriched their lives, enabling them to pursue more activities. However, persons who sensed that they lacked potent ways of alleviating an attack expressed no willingness to experiment with triggers, as the symptoms of the attack were experienced as worse than the limitations of avoidance.

Possessing potent ways of alleviating attacks was understood as increasing one's power to be in control of one's life, by making it possible to function during an attack. It is possible to draw parallels between the present finding and the findings of Heath, Saliba, Mahmassani, Major, and Khoury (2008), where persons' perception of whether pharmaceutical therapies were effective in revealing or preventing their migraine attacks was connected to their sense of having internal locus of control. The present study further adds that having potent ways of handling attacks is a prerequisite for being able to focus on increasing one's general well-being, which in turn seems to affect positively the experience of living with migraine.

The persons who had reached an acceptance of migraine and viewed their disorder as a part of life had fewer feelings of guilt and took the attitude that they wanted to make the best of the situation. Those who had not reached peace of mind through acceptance struggled more to be able to function, as well as those who were not afflicted by migraine, and being unable to do so, they were more likely to see themselves as failures. This difference in outlook indicates

that acceptance influences well-being. Acceptance has been shown to have relevance to the experience of migraine, irrespective of headache severity, by creating increased perceived control, a higher level of activity, and lower levels of pain-related interference (Chiros & O'Brien, 2011). The findings of the present study showed that the attitudes of the surrounding world, especially those of close friends, family, and influential people such as physicians, affected the person's inner sense of acceptance of being afflicted. Therefore, it is troublesome that previous research has shown that persons with migraine have experienced other people questioning the seriousness of their migraine and not been taken seriously by personnel in healthcare (Cottrell et al., 2002; Moloney et al., 2006; Rutberg & Öhrling, 2012). We suggest that more information about migraine can increase the understanding of living with it, and according to van Manen (1997), hermeneutic-phenomenological research can contribute to greater thoughtfulness and tactfulness towards others, although such a transformation requires an openness to change. Moreover, acceptance and commitment additive therapy among women with migraine has proven to be an effective treatment of headache disability, emotional distress, and the affective dimension of pain (Mo'Tamedi, Rezaeiaram, & Tavallaie, 2012). The findings of this study indicate that acceptance is an aspect that could be considered in the treatment of migraine in order to assist persons to feel well.

Methodological considerations

The 19 persons who participated in this study had a wide range of experience of managing life to feel well while living with migraine. According to Norlyk and Harder (2010), the participants of a phenomenological study must have experience of the phenomenon under study, but it is not equally necessary to have a variation in age, gender, and background. One limitation of the present study could be that 11 of the 19 persons with migraine were recruited by their physical therapist. Their participation in physical therapy could indicate that they were active in wanting to improve their health. To address this issue, we included another eight persons who were not actively participating in physical therapy, and we thereby strived to collect experiences of a broader variation. Another limitation was that we did not collect data on the participants' use of premedication or their satisfaction of it. It is possible that the participation in physical therapy indicates that they are not using or are not satisfied with their premedication. This interpretation is enhanced by the findings of another study that some of the persons

also participated in, showing that the strong motive for them to participate in physical therapy was to decrease their intake of medication or not being satisfied with their medication (Rutberg, Öhrling, & Kostenius, 2013).

To enhance the quality of this hermeneutic-phenomenological study and to maintain openness to the phenomenon under study, we formulated the research question driven by a sincere curiosity (van Manen, 1997). Furthermore, we held numerous discussions through the study and made notes about our preunderstanding and presumptions, for example, about managing life with migraine and how we ourselves manage life to feel well. By adopting Drews (2001) suggestions on revealing one's preunderstanding and assumptions, we became more aware of our beliefs, of our ways of viewing the phenomenon, and of some views that we had been unaware of. Even though there is always more than one possible interpretation in hermeneutic-phenomenological research, we hope that the interpretations that we have found to be the most probable in this study can encourage health professionals to act with thoughtfulness when meeting persons with migraine.

Conclusions

Much of the earlier research dealing with the ways in which persons with migraine manage their lives has focused on preventive strategies. However, feeling well while living with migraine requires more than merely averting the threat of migraine. The findings of this study show that managing life to feel well while living with migraine involved striving to build a basic foundation of safeness, through handling triggers and the symptoms of migraine. Managing life to feel well also meant striving to amplify the good in life, by acting thoughtfully to increase one's energy and joy, as well as by finding peace with being afflicted with migraine as it meant finding a sanctuary from which migraine was easier to handle emotionally. Therefore, it is a necessity for persons to use both preventive and promotive strategies to feel well when living with migraine.

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Paper III

RESEARCH ARTICLE

Professional tools and a personal touch – experiences of physical therapy of persons with migraine

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Abstract

Purpose: The aim was to explore the lived experience of physical therapy of persons with migraine. **Method:** Data were collected by conducting narrative interviews with 11 persons with migraine. Inspired by van Manen, a hermeneutic phenomenological method was used to analyse the experiences of physical therapy which these persons had. **Results:** Physical therapy for persons with migraine meant making an effort in terms of time and energy to improve their health by meeting a person who was utilising his or her knowledge and skill to help. Being respected and treated as an individual and having confidence in the physical therapist were highlighted aspects. The analysis revealed a main theme, "meeting a physical therapist with professional tools and a personal touch". The main theme included four sub-themes, "investing time and energy to feel better", "relying on the competence of the physical therapist", "wanting to be treated and to become involved as an individual" and "being respected in a trustful relationship". **Conclusions:** The therapeutic relationship with the physical therapist is important and the findings of this study can increase awareness about relational aspects of physical therapy and encourage thoughtfulness among physical therapists and other healthcare professionals interacting with persons with migraine.

Keywords

Interaction, migraine, physiotherapy, therapeutic relationship

History

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► Implications for Rehabilitation

- Physical therapists use both professional tools and a personal touch in their interaction with persons with migraine and this article can increase physical therapists' awareness and encourage thoughtfulness in their professional practice.
- Being respected and treated as an individual and having confidence in the physical therapist are important aspects of the therapeutic relationship and indicate a need for patient-centred care.
- By making the effort of spending the time and energy required, physical therapy could be a complement or an alternative to medication to ease the consequences of migraine.

Introduction

Living with migraine means having a chronic disorder that causes attacks of severe headache, sometimes with associated symptoms such as nausea and phono- and photophobia [1]. Besides the attacks, life is affected by the uncertainty of future attacks and by lifestyle changes made to avoid triggering an attack [2,3]. The disability associated with migraine is substantial [4], and in 2001 the World Health Organization [5] listed migraine among the top 20 causes of disability.

In the guidelines for treatments offered to persons with migraine, medications are used primarily, but non-drug alternatives are also recommended [6]. However, the use of

medication is not uncomplicated. Bigal et al. [7] found that overuse of pharmaceuticals was a common reason for migraine developing into chronic daily headaches. Moreover, earlier studies have described migraine sufferers' fear of becoming addicted and fear of the side-effects of frequent use of medication [3,8]. Among non-drug interventions, acupuncture has been found to be at least as effective as preventive medication [9] and cognitive behavioural therapy and bio-behavioural training (i.e. biofeedback, relaxation training and stress management) are promising treatments [10]. Physical therapy offers many of the recommended non-drug treatments for migraine, and a review has shown that a combination of physical therapy interventions was most beneficial in the treatment of migraine [11].

Physical therapy is concerned with identifying and maximising the quality of life and movement potential through promotion of health, prevention of illness or rehabilitation among persons, who need to develop, maintain or restore movement and functional ability [12]. An important part of physical therapy is the

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interaction between the physical therapist and the person who needs help and a good relationship can promote health and well-being [12]. Previous research has shown that a good patient–therapist relationship is likely to affect the outcome of physical rehabilitation positively [13,14]. The outcome seems to be affected by the physical therapist’s sensitivity and ability to negotiate a common ground [15]. This might be even more important concerning persons with migraine, since both Brandes [2] and Edmeads [16] have stated that effective patient–therapist communication is a key factor in migraine prevention. Further, several studies [17–19] have reported that persons with migraine have frequently experienced not being taken seriously by healthcare personnel. Examples of the complaints were that physicians lacked sympathy and dismissed migraine as an insignificant disorder or just prescribed a medication without listening to the needs of the persons with migraine. Consequently, it is important to explore their experiences of health care further. Apart from a study showing the experience of acupuncture of women with migraine who had been given such treatment by physical therapists [20], there is to our knowledge no study showing how persons with migraine experience physical therapy.

To improve physical therapy, Potter et al. [21] emphasised the importance of physical therapists having an awareness of their part in the intervention and the interaction with the patient, and they concluded that more research was needed, especially from the patient perspective. Therefore, this study aims at exploring the lived experience of physical therapy of persons with migraine.

Method

Design

To fulfil the aim of the study, we chose to use a qualitative research design with a phenomenological approach. According to van Manen [22], phenomenological research begins in the lifeworld, and he relies on Husserl’s epistemology in arguing that phenomenology means understanding the meaning of lived experiences and of being in the lifeworld. According to Drew [23], researchers as residents of the lifeworld are creative co-contributors together with that world and understand phenomena from the perspective of their particular situatedness. Their pre-understanding and beliefs contribute to their perception of the phenomena under study and cannot be suspended or bracketed [22]. In addition, Drew [23] emphasises that self-awareness is the foundation of objectivity in phenomenological research, and therefore researchers must give clear information about how they are connected to the phenomena under study. The present authors have different experiences of being health caregivers: one of us as a physical therapist in primary care (Stina Rutberg), one as a nurse (Kerstin Öhrling) and one as a health consultant (Catrine Kostenius). Moreover, we have experiences of being patients receiving physical therapy, although none of us has a lived experience of having migraine.

Ethical considerations

Permission was obtained from the relevant healthcare managers before a number of physical therapists were contacted and asked for their help in communicating information on the study to their patients. After being informed about the study and having been told that they could change their mind about participating at any time without having to provide an explanation, a number of persons with migraine gave their informed consent to participation, and full confidentiality was assured. The Regional Ethical Review Board at Umeå University in the city of Umeå in Sweden approved the study (reference no. 08-182M).

Participants

Physical therapists at 38 primary care clinics in the northern part of Sweden were contacted by phone and asked if they at that point in time were treating any persons diagnosed with migraine. At nine of those clinics there were physical therapists treating at least one person with migraine. Information about this study was sent to the therapists at these clinics by post and they handed out information about the study to their patient/patients. To be included in the study, the participants were required to be at least 18 years old, to have been diagnosed with migraine, to be receiving physical therapy from a physical therapist for their migraine and to be able to speak Swedish.

Eleven persons, nine of whom were women and two were men, answered and agreed to participate in the study and they were between 20 and 69 years old. Nine persons had had their migraine diagnosis for 9–59 years, and two persons had had their symptoms and diagnosis for about 1 year or less. The number of migraine attacks varied as follows: 3–8 attacks per year for two persons, 1–4 attacks per month for 7 persons and 5–8 attacks per month for two persons. Four persons were attending their first period of physical therapy and two persons were attending their second period. Five persons have been attending physical therapy for different periods during the previous 3–20 years. The participants had experience of many different physical therapy interventions, e.g. exercises, stretching, relaxation training, stress management, acupuncture, massage, working on posture change and ergonomics and learning strategies for how to stay healthy.

Data collection

The persons interested in participating were contacted by phone and given additional information about the study, and the time and place of an interview were decided. Six interviews took place at the home or workplace of the participant, and five interviews were conducted at Luleå University of Technology, all of them held in an undisturbed room. Interviews with a narrative approach were performed by the first author. To capture the participants’ experience of physical therapy, the interview started by inviting them to tell their story: “Please tell me about your experience of receiving physical therapy for your migraine”. To encourage the persons to elaborate their narratives, the interviewer asked questions like “How did you feel then?” and “Can you tell me more about...?”

The participants were asked to draw a picture of their experience of physical therapy when the interview reached the point when they did not have any more information to add to their stories. Thereafter the interview continued with narrations about the picture, starting with the questions, “Could you please tell me about your drawing?” and “What feelings and associations do you get when you look at your drawing?” Nine of the 11 participants chose to draw a picture. The interviews held before and after drawing the picture lasted about 40 min each. They were tape-recorded and transcribed verbatim with indications of non-verbal pauses and emotional expressions.

Data analysis

Inspired by van Manen [22], the process of analysis involved the interrelated phases of seeking meaning, theme analysis and interpretation with reflection, all of which considered both the parts and the whole of the text. The analysis phases were not performed in a stepwise fashion, but rather were a movement back and forth to reach understanding of the phenomenon. The analysis started with a verbatim transcription of the recorded interviews, after which the text was read several times to obtain a sense of the collected meaning or meanings in all the experiences described by

Table 1. Our evolved pre-understanding.

- A healthy life is the equilibrium of physical, psychological, emotional, social and existential well-being.
- Physical therapy is both an intervention and an interaction between the physical therapist and patient. The effects of the intervention and the interaction are intertwined and affect each other.
- Physical therapy aims primarily to treat the human via the body, and it has the potential to promote health and well-being.
- There are no stereotypes for "the good/bad physical therapist"; rather the experience of receiving "good/bad physical therapy" depends on the patients' experience of how their needs are met.

the persons with migraine. During the phase of theme analysis, the entire text was reread and phrases and sentence clusters that seemed to be thematic were marked as meaning units. Motivated by a sincere desire to explore our own pre-understanding, suppositions and assumptions, we adopted Drew's [23] suggestions for structuring pre-understanding in the following steps. The search for our pre-understanding started with an exploration of our own feelings and motives steering our choice of meaning units. We wrote down statements about the meaning units, producing a text that revealed something about our own understanding, and we tried to capture the questions which the statements were answers to. We added our own experiences of the written statements, particular situations where we were a patient and a caregiver, and the feelings connected to these experiences. The questions and the summations of the statements provided knowledge about our collective understanding and presumptions. To elucidate the point of departure of our understanding, we have made a summation of our collective pre-understanding and presumptions in this study (Table 1).

The data analysis continued thereafter with a return to the text and meaning units and we asked ourselves the following question concerning each meaning unit: "What does this meaning unit reveal (thematically) about the lived experience of physical therapy?" In the data analysis, we remained true to van Manen's [22] (p. 34) description of the "inventive thoughtful" attitude. First, we reflected on the data that we had started writing down and then we alternated between reflection and rewriting in a back-and-forth movement, to illuminate the meaning of and the meaningful interconnections between all the data. The preliminary themes were discussed with research colleagues who had experience of physical therapy or other healthcare professions. Moreover, some of these colleagues had experience of working with qualitative methods, including hermeneutical phenomenology. This procedure supported reflection and provided new understanding which resulted in some minor changes in the names of the themes and in part of the text changing its position. During the procedures of analysing and reflective writing, our understanding evolved and the final structure emerged.

Findings

The analysis revealed one main theme and four sub-themes, which captured the lived experiences of physical therapy of persons with migraine (Table 2).

Meeting a physical therapist with professional tools and a personal touch

The analysis resulted in an understanding of the fact that physical therapy meant making an effort to improve one's health by meeting a person who utilised his or her knowledge and skill to help and by participating in an intervention. One interpretation was that the physical therapists used several professional tools and their personal touch in the interaction with the persons with migraine, which had the power to strengthen both the persons with migraine and the therapeutic process. The professional tools were understood to be the therapist's competence in physical

Table 2. Overview of the main theme and sub-themes.

Main theme	Meeting a physical therapist with professional tools and a personal touch
Sub-theme	Investing time and energy to feel better
Sub-theme	Relying on the competence of the physical therapist
Sub-theme	Wanting to be treated and to become involved as an individual
Sub-theme	Being respected in a trustful relationship

therapy, communication skills and ability to build a trustful relationship and meet individual needs. Our understanding was that the personal touch applied by the physical therapist in his or her interaction with the persons with migraine comprised both actually touching them physically and, more metaphorically, treating them in a personal manner. One highlighted aspect was being treated as an individual and examples of that were occasions when the persons with migraine were seen and acknowledged, which was communicated through dialogue and touch. The therapeutic relationship with the physical therapist played an important role in the experience of the persons with migraine and, in this connection, being able to trust and feeling trusted were crucial components. Even if the intervention was a tool for reaching alleviation, the satisfaction with the intervention rather referred to the persons' experience of the competence of and the relationship with the physical therapist. Together, the intervention, the relationship, the expertise of the physical therapist and the persons' with migraine own efforts composed the crucial parts of physical therapy. The following metaphor is one example of the lived experience of physical therapy.

[It is as if] the physical therapist is a watering can, and the flower is actually us coming together and our feelings... first the exterior is happy and brightly coloured... then you have roots that are just painful and black-red, yes the pain... and the physical therapist tries... to water or take care of that ugly little black-red... [like] a helping hand... a watering can that can help the flower to grow... it [the flower] is the interaction, but it is also me... and here are some black details, because the bad things are always there, but the main thing is that the watering can [the physical therapist] wants this bud to grow... and be able to flower...

Sub-themes in this main theme were "investing time and energy to feel better", "relying on the competence of the physical therapist", "wanting to be treated and to become involved as an individual" and "being respected in a trustful relationship."

Investing time and energy to feel better

Engaging in physical therapy for persons with migraine meant investing time and energy to abort or ease the consequences of migraine. The desire to decrease the intake of medication was a strong motive for engaging in physical therapy and, in cases when medication did not work, physical therapy was considered a possibility of reaching alleviation. Physical therapy was experienced as being a way for the body itself to heal or alleviate pain

and not as something that was added to the body, like medication. ‘... one should not become too dependent on or take too much medicine; this [acupuncture] is actually also a form of medication, it releases something in the body that is preventative, but compared to medicine it feels natural...’

The outcome of physical therapy could mean, besides the alleviation of migraine, increased awareness of one’s own body, relaxation and a feeling of increased energy and strength. When the outcome meant decreased suffering from migraine, it was experienced as a relief in the psychological and existential areas as well. ‘I have really been helped by this [the physical therapy]. I can still get a migraine... but this acupuncture treatment was a boost, it is as if I have entered a new phase in life...’ However, sometimes it was difficult to know what was influencing the migraine attacks and if the relief from migraine was due to the physical therapy or something else.

The persons with migraine highlighted the importance of the physical therapy interventions providing the reward of improved health and decreased pain. When the symptoms of migraine were a burden, it was considered worthwhile to take the time required for a visit to a physical therapist. The time spent on physical therapy meant not only an interruption in the daily activities and could be experienced as frustrating, but also as an opportunity to spend time and focus on oneself. ‘... sometimes I can feel that it is an annoying feeling if I am stressed and have much to do, that it is hard to lie still, but... I try to make it a positive moment, having time for myself...’

Relying on the competence of the physical therapist

The importance of the skill and knowledge of the physical therapist was emphasised by the persons with migraine. Having confidence in the physical therapist meant decreased worry and fear and could make it possible for the persons with migraine to have the courage to try something which they would normally not try, such as acupuncture. The persons with migraine expressed that receiving acupuncture treatment was a special situation where they felt vulnerable, since acupuncture had the potential to be harmful. In these situations it was crucial that the person with migraine should have confidence in the physical therapist to create a feeling of security. The confidence felt in the physical therapist also influenced the perceived appraisal of the intervention.

... she knows exactly what I need and I felt that it gave results, everything we did, it was so obvious, but oh God... [first] I thought that it couldn’t help, but it did... you know, me clenching my teeth at night, which can also be a reason why my neck is so tense, and then she thought of a method I could use to relax when I am sleeping, so she has answers to everything...

Confidence in the knowledge of the physical therapist was mediated through the individual physical therapist’s personal manner, i.e. way of acting, touching and treating the person, as well as through his or her communication skills. Equally important as or even more important than communication skills was the fact that the persons with migraine sensed that the physical therapist knew what he or she was doing, as recognised in his or her touch. A skilled physical therapist’s touch felt professional and mediated a feeling of knowledge and security. ‘... it’s quite amazing too, he [my physical therapist] feels... just by feeling, that there is the right spot [acupuncture spot]... I have complete trust in him; I could almost be unconscious and still be there, I totally trust him’. However, experiencing being touched by someone who felt unsure and was somewhat clumsy mediated

the feeling that this was an inexperienced physical therapist. It was difficult for a physical therapist to compensate for a lack of practical experience, even by demonstrating theoretical knowledge. When a physical therapist found and confirmed a person’s tender spots, trust in his or her knowledge increased. Accordingly, it seems that knowledge of and skills in performing the intervention were more important than knowledge of the disorder. ‘She knew I was searching for help for my migraine, but she talked more about tension headache actually, but that is not what I have... but I thought; well okay... she was good anyway because I got better...’ Experiencing a positive outcome from physical therapy increased the person’s confidence in the physical therapist. However, when the intervention was considered to be effective, some persons perceived the physical therapist as being less important.

Wanting to be treated and to become involved as an individual

Going to a physical therapist meant engaging in a therapeutic relationship and to some extent being dependent on another person for the treatment of one’s migraine. The persons with migraine embarked upon physical therapy with individual needs and their needs changed sometimes during the therapeutic process. They wanted to be treated by a physical therapist who was interested in them and tried to meet their needs. Sometimes they wanted someone who could provide them with knowledge and teach them how to manage their migraine on their own in the best possible way. In some situations they needed to be taken care of, for example, when they felt vulnerable or ill. The physical therapist’s ability to meet these individual needs influenced the person’s satisfaction with the intervention.

... you have to struggle on by yourself too; no one is telling you to go and do your exercises and that’s all up to me, but the physical therapist is a good tool to get you started and to guide you in doing the right things, so that you don’t go and make things worse... they can explain how your body functions, and in that way you are learning all the time...

It was found that the persons with migraine considered it important to be treated with individual approaches, and not to have an intervention performed by routine. ‘... she [my physical therapist] is really good... she cares about me and makes me feel that I’m not only one in a crowd, she asks me how I feel today... and if we shall insert the needles...’ Involvement in the therapeutic process and the decision-making was understood to be a part of the individual care. At the beginning of a period of physical therapy, the physical therapist was usually considered as being the one in charge and the involvement in decisions of the persons with migraine mostly concerned answering questions and being informed and tutored. Persons who had been undergoing physical therapy for a long time often experienced that they could be more involved in the decisions and they had clearer perceptions of what was good and effective for them. However, when the level of trust in the physical therapist was high, this meant that it was more natural that the physical therapist should make suggestions and choose interventions, even though it was preferable that collaboration should take place with the persons being treated.

I trust him completely... he knows what he is doing; I have seen that it gives results and when he asks me if I would like to try something, I say of course I will, I will do anything that can help me.

One important aspect of being involved was the availability of the physical therapist. The persons with migraine expressed

feelings of vulnerability when they did not know how available the physical therapist was, and a woman with migraine expressed her worries as follows: ‘‘I do not dare to think about what would happen if I was not able to go to the physical therapist anymore’’. When availability of the physical therapy was assured in advance, for example when the physical therapist had said, ‘‘Just call me if you get worse’’, this gave a sense of comfort and security. By knowing that there was help to be obtained if necessary, the persons with migraine felt that they were able to cope better. In addition, being able to make an appointment quickly when calling the physical therapist gave the feeling of being prioritised and taken seriously by the physical therapist.

It [being able to call if I get worse] gives me a sense of security, knowing I can come and get this help, which she is so good at, and that I can get better if it starts all over again.

Being respected in a trustful relationship

Feeling important and respected was highlighted by the persons as a valued aspect in their therapeutic relationship with the physical therapist. It was crucial to the persons with migraine to be treated by a physical therapist who believed in them and showed a commitment to providing help. A sense of being understood was a key factor in the communication with the physical therapist and a pre-requisite for their ability to share everything concerning their disorder and how it affected their life. In addition, feeling free to speak about everything was expressed as a liberating experience.

... I feel that I'm not being neurotic or anything like that... [I can tell her about] the smallest pain I feel and she can say that the reason is this or that, and this is what you can do... I understand that it is probably not so bad after all... but [it is easy for my physical therapist] to think... that [I] should be able to tolerate some pain and so on, but with her I never feel like that, she understands and tries to help me as much as possible...

A sense of being respected was mediated not only by communication, but also through the physical therapist's actions, for example by the physical therapist showing caution and being attentive to the reactions of the person with migraine. When the physical therapy included undressing, which was sometimes experienced as causing discomfort and a sense of being exposed, it was crucial that the person with migraine should be treated with respect.

... one has to take off so much of one's clothing [in the physical therapist's consultation room] and I can feel that sometimes that... is not so nice; I know I must do so... he would never... do anything that would make me feel uncomfortable and that is important; I feel secure... but I feel quite naked when I'm there... but I feel cared for too, having a soft pillow... and a towel over me, then I feel less... vulnerable...

Several persons with migraine had had previous experiences of not being taken seriously by healthcare professionals, and they described this as being made to feel invisible and sometimes worthless and a waste of the staff's time. On occasions like these, it was easy for them to hide and understate the severity of their own symptoms.

[A good reception] is to be treated with... curiosity, perhaps not curiosity... but... at least not being greeted

with ‘‘What are you doing here?’’ and not having a feeling that you are not being believed, compared to my physical therapist, who really listens to me and understands and tries to help and explain...

When the physical therapist remembered previous expressed needs, requests or personal information, which did not necessarily need to be linked to the intervention or disorder, a feeling of being seen and important arose among the persons with migraine. When the physical therapist was well acquainted with the person and knew the history of his or her disorder, it was considered hard to start all over again with a new physical therapist and to have to retell the whole of one's case history. ‘‘[My physical therapist] knows my background and everything [about my illness]. We usually talk a lot about stress and stress management and he notices when I am stressed... it is extremely valuable that he knows all about me...’’. When the person with migraine sensed that he or she had got to know the person behind the role of the physical therapist, the therapeutic relationship was strengthened as long as the roles were intact; for example, it was not acceptable for the person with migraine to feel sorry for the physical therapist. A prolonged intervention period often meant mutual sharing of personal experiences between the person with migraine and the physical therapist. The persons with migraine expressed a satisfaction when they could offer the physical therapist advice in areas where they were experts. They also felt valued when the physical therapist shared his or her personal experiences in other areas than health care. ‘‘... we talk quite a lot... and when she had been away... [and said,] ‘I must tell you about...’ I felt so, it was amazing what she shared with me, we have a good connection’’.

Discussion

This phenomenological study has attempted to illuminate the lived experiences of physical therapy of persons with migraine and our interpretation of the narrated experiences has revealed one main theme, ‘‘meeting a physical therapist with professional tools and a personal touch’’. Meeting a physical therapist meant a possibility of improving one's health, but demanded an effort involving time and energy on the part of the person with migraine. The physical therapists possessed an array of professional tools which consisted of communication skills, the ability to instil confidence in their competence and the ability to build a trustful therapeutic relationship and meet individual needs, and they used these tools in their interaction with the persons with migraine. Our understanding also reveals that the persons with migraine were treated with a personal touch, which comprises both being treated in a personal manner and actually being touched physically. The use of the professional tools and the application of a personal touch were interlaced and constituted crucial components of the therapeutic relationship with the physical therapist.

Our findings indicate a need to establish a trusting therapeutic relationship built on good communication and confidence in the physical therapist. The physical therapist's personal manner and communication skills influenced the persons' confidence in the physical therapist and their feeling of being respected, involved and individually treated. The importance of the physical therapist's ability to communicate has been emphasised in several earlier studies on patients' perceptions of physical therapy and the qualities of a good physical therapist [24–27]. Slade et al. [27] concluded that a willingness to listen and communicate effectively may improve the patients' satisfaction with care. Further, Cooper et al. [25] stated that communication is the most important dimension of patient-centred physical therapy. Our understanding is further that the relationship with the therapist

was strengthened when the person with migraine got to know the person behind the role of the physical therapist, for example by sharing experiences beyond the issues of physical therapy. According to Tickle-Degnen [28], the therapist and the patient should bond and develop a friendship, which is useful for communicating respect. However, this friendship is not equivalent to a social friendship.

The persons in this study highlighted a need to be respected and, most of all, not to be perceived as someone who is just complaining. It is possible that the need for a trusting therapeutic relationship is more explicit among persons with migraine, since, as Rutberg and Öhring [3] have found, they live with the fear of not being believed. Further, Cottrell et al. [18] has reported that several persons with migraine have experienced being dismissed by healthcare services and that they desire a collaborative therapeutic relationship, to improve the understanding of the person with migraine before treatment is offered. However, the need to be trusted by the physical therapist is not an isolated experience for persons with migraine. Persons with chronic low back pain have stated that healthcare personnel have sometimes not taken them seriously and that they want a confidence-based partnership with their physical therapist [27]. Further, persons with musculoskeletal problems have stated that they want the physical therapist to make them feel understood and respected and demonstrate empathy [26].

Confidence in the physical therapist has been emphasised in this study and, when the persons with migraine had confidence, this meant having a lower level of worry and fear and affected their appraisal of the intervention. This is similar to the findings of Kidd et al. [26], who further argued that, within a good therapeutic relationship, the physical therapist's expertise and self-confidence can create a confident patient who can be self-directed after a certain period of treatment. The physical therapists' knowledge of migraine was not one of the factors highlighted by the persons in this study; rather, the physical therapists' competence was considered to consist of their skill in performing interventions and their knowledge of the interventions and the body, as mediated through communication and a skilled and experienced touch. This differs from the studies of Cooper et al. [25] and Slade et al. [27], where persons with low back pain perceived the physical therapist as an expert on their diagnosis, and their confidence in their physical therapist related more to his or her ability to communicate his or her expertise.

The findings of this study have revealed that the persons with migraine embarked upon physical therapy with individual needs which were not constant, but instead changed during the therapeutic process. The physical therapists' ability to meet these individual needs affected the persons' satisfaction with physical therapy. Potter et al. [24] concluded that, by actively seeking patient input, physical therapy can be more patient-centred and beneficial. Being treated as an individual was in this study understood to be closely connected with being involved in the therapeutic process and decision-making. The importance of being involved in rehabilitation was emphasised by Cott [29], who found that persons with chronic illness and disability regarded patient-centred care as the equivalent of being actively involved in managing their health care and their rehabilitation process. In addition, May [30] described how patients receiving physical therapy wanted to be listened to and involved, and to have treatment which could be seen as a consultative process, which met their individual needs, rather than treatment given as a prescriptive process. In this study, the desire of the persons with migraine to be involved in decisions varied, depending on where in the process they were and how much confidence they had in the physical therapist. This differs to a certain extent from the findings of Cooper et al. [25], which showed that patients

generally did not want to be involved in decisions as long as they received good explanations. One important finding in this study was that comfort and security could be obtained through a pre-arranged availability of physical therapy and that the persons with migraine were able to cope better merely by knowing that help was available. Access to physical therapy has been highlighted as an important dimension in patient-centred physical therapy [25]. Therefore, our proposal is that the physical therapist should offer persons with migraine the opportunity to be involved in the physical therapy process. In addition, we suggest that the process would benefit from the physical therapists using both perceptiveness and adaptability to meet their individual needs.

The findings of this study show that the outcome of physical therapy for persons with migraine could extend beyond physical relief, by giving relief in the psychological and existential areas as well. This mirrors the finding of Rutberg and Öhring [20] that women who received acupuncture treatment for their migraine, given as a physical therapy intervention, felt that they could live life to the fullest when the migraine decreased in severity. A strong motive for engaging in physical therapy was the possibility of decreasing the intake of medication, and sometimes it was used as an alternative to medication. Even though physical therapy was considered a way for the body to heal itself, the strongest motivator for continuing was the fact that physical therapy resulted in the reward of increasing the person's feeling of health and well-being. As many of the non-drug interventions recommended in research for migraine [9–11] are performed by physical therapists, it is surprising that persons with migraine only visited nine of the 38 clinics that we contacted. We have not found any research showing how common it is for persons with migraine to attend physical therapy, but this seems to be a low number considering the fact that about 13% of the population in Sweden suffer from migraine [31]. One reason for this could be the time and energy which a person with migraine has to invest in treatment, but further research is needed to explore why they do not attend physical therapy to a greater extent.

Although we did not explicitly ask the persons with migraine participating in this study about their experience of the therapist or their relationship with the therapist, the major part of the findings relates to that. Our understanding is that their accounts concerning satisfaction with the physical therapy treatment related to the confidence which they had in the physical therapist and his or her ability to meet their individual needs and to build a trusting relationship. This can be compared with the findings of Hush et al. [32], which showed that the key determinants of patient satisfaction were the attributes of the physical therapist and the process of care. In addition, May [30] concluded that satisfaction is a reflection of the quality of care and the care process, besides being an important measure of the outcome. The findings of this study reinforce the importance of paying attention to the patient-therapist relationship in physical therapy, which is a factor that previous research has suggested as being important for the outcome [13–15]. The effectiveness of interventions versus interaction in physical therapy has been discussed, and Miciak et al. [33] argue in favour of common factors in physical therapy affecting the outcome, like therapist qualities, relationship elements and client characteristics. According to Tickle-Degnen [34], research on the therapeutic relationship can provide important information and shape an evidence-based practice in rehabilitation.

Methodological considerations

Hermeneutic-phenomenological research has the potential to deepen the personal insight of persons who are open to change, and thereby enhance their ability to act with more thoughtfulness

and tactfulness towards others [22] (p. 7, 23). Since the aim of this study was to explore the lived experience of physical therapy of persons with migraine, it was important that the data collected should contain rich information and a broad variation of experience. The persons with migraine participating in the study had experience of a wide range of different interventions and some of them had attended physical therapy only four times, while others had 20 years' experience of physical therapy, which indicates both a richness and a variation of experience. To facilitate the interviews and deepen the narration, we asked the persons with migraine to draw a picture of their experience of physical therapy when they did not have anything more to add to their initial narration. The pictures made it possible for them to recall and express further their experience of physical therapy, as well as to summarise the experience that they had previously narrated. We chose to use only the narration about the picture in the data analysis and not the picture itself. According to Guillemin [35], drawing pictures is a process of knowledge production and, when the participants in a study make their own interpretation of their drawing, this validates the drawing further as a research method.

The finding of a phenomenological study is not only based on the empirical world, it also derives from the researcher's consciousness of the empirical world [36]. Therefore, the constructed truth value of the study depends on how rigorously and effectively the researcher's subjective experience of the phenomenon is explicated and recognised as a contributor to the phenomenon [36]. To meet this criterion of quality, we spent a great deal of time exploring our own pre-understanding and assumptions, as well as our experience of being a patient, a healthcare professional and a researcher, in a structured way. To challenge our pre-understanding further and to enhance the quality of the study, we presented the preliminary findings and discussed them with fellow researchers who had experience of qualitative research methods and health care. We used our pre-understanding as a point of departure and we tried to evolve our horizon of understanding. Even though complete self-understanding is not possible [23], we have attempted to explicate our self-understanding to give the reader an understanding of our influence on the research.

A possible limitation of this study may be that having a positive experience of physical therapy could have enhanced the willingness of the patients contacted to participate in the study, but, even if this is so, our findings still present a wide range of experiences comprising both positive and negative aspects.

Conclusions

When persons with migraine were asked about their experiences of physical therapy, their narrations mostly related to their experience of and therapeutic relationship with the physical therapist. In the patient–therapist interaction, it was important to be respected and to be treated as an individual, as well as to have confidence in the physical therapist. This indicates the importance of physical therapists being conscious of how they use their professional tools and their personal touch. The findings in this study can increase awareness and encourage thoughtfulness among physical therapists and other healthcare professionals interacting with persons with migraine.

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Declaration of Interest

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Paper IV

ORIGINAL ARTICLE

Experiences of acupuncture among women with migraine

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Abstract

The aim of this study was to describe experiences of acupuncture treatment among women with migraine. The study was based on narrative interviews with 10 women in the northern part of Sweden. The interview text was analysed using qualitative content analysis and the results were grouped into two categories: “experiences during acupuncture treatment” and “experiences after acupuncture treatment” and five subheadings. The experience of acupuncture during treatment varied between women, over time, and depending on external circumstances. Women stated that the patient–therapist relationship affected the experience both during and the outcome after acupuncture treatment. The results showed that acupuncture relieved pain, decreased the use of pharmaceuticals and increased emotional strength. When the migraine disappeared or was lessened, women felt that they could live life to the fullest again and felt that family and work did not suffer, as they did before the acupuncture treatment. Women felt a feeling of control over migraine and experienced safety in the effect of acupuncture. In conclusion, acupuncture seems to relieve the consequences of migraine and can be viewed as an alternative for physiotherapists in treating persons with migraine.

Key words: *Acupuncture treatment, content analysis, migraine, pain, qualitative research*

Introduction

As in the rest of the world, migraine is a common disorder in Sweden and affects more women than men (1). Migraine influences the quality of life negatively, in several ways. One in every three migraine sufferers believes that their problem controls their life (2) and the impact extends to family, work and social relationships (3,4). Treatment with acupuncture has been found to improve the quality of life among persons with migraine (5).

The value of acupuncture in the treatment of migraine is controversial owing to methodological quality related to insufficient control interventions, lack of detail concerning needling and the use of diagnostic criterion (6). The authors (6) concluded that until further research is published, with verification of the benefits of acupuncture in the treatment of migraine, provision of acupuncture should not be expanded or withdrawn (6). There were no differences between sham acupuncture and ordinary acupuncture in the treatment of patients for migraine, but both groups were more effective than a

waiting list control (7). Acupuncture reduced the frequency of migraine attacks and had the best outcome over time when compared with those from TENS and laser therapy (8). Persons with chronic headache, predominantly migraine, suffered from a significantly reduced number of headaches through acupuncture treatment in addition to standard care, when compared with only standard care (5). The authors draw attention to the fact that further research on the effects of acupuncture treatment among persons with migraine is needed.

Women with headache who received acupuncture had significant differences in quality of sleep, depression and satisfaction with life in comparison with the control group (9). Because persons with migraine experience a negative impact on their quality of life (10), it is interesting to elucidate what experiences acupuncture treatment brings to this target group. The importance of acupuncture in chronic diseases comes to light in the study of Paterson & Brittsen (11). Patients reported more energy and positive changes in personal and social identity. Since the participants in the study had

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many different chronic diseases, there are still questions about the importance of acupuncture in the treatment of migraine. However, the authors emphasize the importance of measuring the whole range of potential treatment outcome of acupuncture in persons with chronic diseases (11). Thus, the aim of this study is to describe the experiences of acupuncture treatment among women with migraine.

Materials and methods

A qualitative design and a content analysis were used to achieve the objective of this study.

Participants and procedure

Ten women from the northern part of Sweden participated in the study. The criteria for inclusion were twofold: (i) persons who had received at least eight acupuncture treatments for migraine in this ongoing treatment set, and (ii) who had been treated by some physiotherapist other than the interviewer, who is one of the authors. The criteria for exclusion were: persons (i) who received other treatments by a physiotherapist at the same time as they received acupuncture, (ii) with severe mental illness and (iii) who did not speak Swedish. The persons who fulfilled the criteria were selected by physiotherapists with experience of acupuncture. The women's ages ranged from 31 to 60 years (Md = 44.5 years) and they had had problems with headaches for between 1 and 34 years (Md = 12.5 years). Nine women had a confirmed migraine diagnosis and one woman had had migraine symptoms for 2.5 years in accordance with the International Headache Society (IHS) criteria for migraine. The present acupuncture treatment period varied from 2 to 24 months (Md = 3 months). The number of earlier treatment sets with acupuncture varied from two to nine sets. Three women were treated for migraine with acupuncture for the first time. The physiotherapists asked their patients about their interests in participating in the study. They handed out written information about the study and informed them that participation was entirely voluntary and that they could withdraw from the study at any time. The first author contacted the participants and answered additional questions, and together with the participant decided the time and place of the interview.

Ethical considerations

Permission was obtained from the relevant managers before the study. The participants gave their written approval for their participation in the study in an

appended envelope and were guaranteed confidentiality and anonymity in the presentation of the result. The study was performed in accordance with the principles of Swedish law (2003:460 §3 and 4) for research ethics.

Data collection

The study was carried out by interviews with a narrative approach that focused on human subjective experience (12). The purpose of the narrative interviews was to stimulate and encourage the women to narrate as freely as possible about their experiences of acupuncture treatment. The interviews started with the question: "Please narrate your experiences of receiving acupuncture treatment. Start with the beginning of this last treatment set and continue to where you are now. There is no wrong or right, so feel free to tell everything." The narration was supported by questions such as, "How did you feel then?" "What did you think then?" "Can you explain more?" (13). The time and place for the interviews was chosen by the women and all the interviews were conducted in a quiet room. The length of the interviews varied between 17 and 118 min. The interviews were tape-recorded and transcribed verbatim.

Data analysis

Inspired by Burnard (14), the interviews were analysed with content analysis, a process described below. The whole text from the interviews was included in the analysis in the following series of steps. Each interview was read through several times to gain a sense of the content. Then a reading of the interviews followed to create coded sections guided by the aim of the study. The coded sections were then sorted out and summed up, and coded into 156 codes very close to the original text. The codes were grouped together into subheadings and categories (Table I). The categories were created according to the requirement that they would be meaningful and exhaustive in ratio to the aim of the study and that no coded section would belong to more than one category. The transcripts were read again to see if any new information emerged, and to comprehend if the name of the category was correct in relation to the text; it was also important to check that no information could be included in two or more subheadings or in both categories. The analysis followed steps 1–14 outlined by Burnard (14), with the exception of step 6, which has been modified, and step 11, which has been omitted. In step 6, two colleagues independent of each other discussed the content of the categories with the authors, and

Table I. Examples of coded sections, codes, subheadings and categories in the analysis.

Coded sections	Codes	Subheadings	Categories
"It hurts a lot when the needles penetrate the skin and they stimulate them and all, it really hurts" (Person 3)	Pain during the needling process	Various bodily experiences	Experiences during acupuncture treatment
"It is almost as you end up in a meditative state ... like you are sitting and looking at the sunset, feeling good, it is like that nice feeling in the body" (Person 2)	Various positive feelings in the body during treatment		
"Physiotherapists who are in a hurry and quickly insert the needles and demand a feeling of chi at once, is not a pleasant experience" (Person 1)	Physiotherapists manner affects the experience during treatment	Situation-related experiences	
"It is important that the environment is calm and the doors are closed ... for example when I lay down with only curtains around, people running around and it is uncomfortable and I can not focus on the treatment" (Person 6)	A relaxed environment is important to the experience during treatment		
"It helps ... I don't need to suffer from headache and nor from the loss of sight, since I have the classic form of migraine" (Person 3)	Migraine disappears	Relief from pain and inconveniences in the body	Experiences after acupuncture treatment
"I always felt frozen, I could not get warm ... it has totally disappeared and I have not changed my eating habits or anything else, I relate the change entirely to acupuncture treatment" (Person 1)	Feeling less frozen after acupuncture treatment		
"I get uplifted after acupuncture treatment, you get happier too when you are uplifted and on the whole you become more harmonious" (Person 8)	Becoming uplifted after acupuncture treatment	Gaining emotional strength	
"Acupuncture makes me relaxed, like a calm feeling, I don't know how to explain, like mentally calm" (Person 6)	Becoming calm after acupuncture treatment		
"I feel safe, it has changed my entire life ... it is a safety in life knowing there are help to get if the migraine get worse again" (Person 7)	Feelings of safety when acupuncture works	Being able to live life to the fullest again	
"Migraine feels like being poisoned, my body doesn't work, acupuncture gives me back the feeling of my body functioning, because migraine isn't only in the head it is the whole physical strength" (Person 1)	Acupuncture restore physical strength, which migraine has taken away		

changes were made to reach consensus. Step 11 was omitted when it was not considered valid to have informants verify the result (15).

Results

The analysis resulted in two categories and five subheadings (Table II). The categories and subheadings are presented in the following text and are

Table II. Overview over categories and subheadings.

Categories	Subheadings
Experiences during acupuncture treatment	Various bodily experiences
	Situation-related experiences
Experiences after acupuncture treatment	Relief from pain and inconveniences in the body
	Gaining emotional strength
	Being able to live life to the fullest again

illustrated with quotations from the interview. The used quotations have been translated word by word and the English corrected.

Experiences during acupuncture treatment

Various bodily experiences. Several women described pain when the needle penetrated the skin and some acupuncture points were more painful; other opinions were that there was only pain when you stimulate the needles. When the needles were in the body, there was occasionally a tingling, torrential feeling in the body. Some women reported a feeling of ending up in a meditative state during the treatment. Many women found acupuncture treatment on whole as a relaxing and positive experience.

Situation-related experiences. Women explained that their own situation in life affected the feeling during treatment, which could vary from time to time; stress and increased muscle tension meant increased

pain during the needle insertion. Women's opinion about the person who gave the acupuncture treatment affected the experience of the treatment. When the physiotherapist was calm and spent time with the woman, less discomfort was experienced during the treatment. A calm and comfortable location in conjunction with the acupuncture treatment contributed to a more pleasant experience in total.

if you have pain and you're calm it doesn't do anything to you, then you hardly feel the needle, it does not matter, but when you then, are truly tensed and so, now it's really going to hurt. (Person 6)

Experiences after acupuncture treatment

Relief from pain and inconveniences in the body. All women experienced an alleviation of pain in some way and foremost with the alleviation of migraine. Two women expressed uncertainty about whether it was acupuncture that had eased the headache. Women compared the alleviation of pain from acupuncture with that from pharmaceuticals, and found that acupuncture had a more specific effect and was experienced more naturally by the body. When receiving acupuncture treatment, women felt that it was the body itself that eased the pain. Women described a reduced need and use of pharmaceuticals, a development that was highly valued. Along with the alleviation of pain, women described a nice feeling in the body.

I have felt that it is actually my body that makes this, it is not something I just take in order to abate pain, it is something I receive, I receive a needle but it is my body that makes me feel better, it feels very more natural and right, though it is my own body that can abate pain. (Person 6)

Women described reduced frequency of migraine attacks and for some women the migraine attacks disappeared. The women who still experienced migraine attacks described the attack as shorter in duration, and with a reduced intensity of pain. Furthermore, there were fewer concurrent symptoms such as loss of sight, nausea, vomiting and agony, with a faster recovery after an attack of migraine. Women reflected that acupuncture gave them better resistance against things that used to lead to migraine like stress, sleeping pattern, and different types of food and beverages. Women, who, apart from migraine also had tension headache and Horton's headache, felt assuagement after acupuncture treatment and for some the tension headache entirely disappeared.

... if one can see over my entire life the absolutely most important effect of acupuncture is that it has helped me with my migraine, it has either taken it away or mitigated it or extended the time between the attacks, it has always had an effect on my migraine. (Person 7)

Women experienced that acupuncture was a quick way to get the body to work. If women had increased inconvenience because of migraine, more acupuncture treatment was needed to achieve the full effect. The effectiveness of acupuncture varied, and women felt that acupuncture gave a better effect when they were calm and relaxed. The outcome of the treatment was also described as increased if the physiotherapist was calm, showed interest in the women, and if they felt secure with him or her.

Apart from the alleviation of pain, women valued the experience of relaxation; they felt more muscle-relaxed and described a liberated feeling. The relaxation was felt as being physically calm, which also gave an alleviation of pain. Women described a sense of increased circulation and warmth in the body, and some women felt that relaxation and the alleviation of pain made them sleep better.

Women felt relief from other inconveniences after acupuncture treatment, for example, painful feet, knees, arms, back, and difficulties related to menstruation and menopause. The experiences of numbness and sensations of cold had also been relieved. Women experienced that their immune defence had improved; colds and rhinitis were less frequent. Some women felt, after occasional treatments, momentary negative effects, which included feelings of frozenness, fatigue and dizziness, while several women did not have any negative experiences at all.

it was a liberating feeling when acupuncture decreased the muscle tension, certainly I can feel a little now and then but it's less. (Person 4)

Gaining emotional strength. Women described increased mental comfort; they experienced a mental relaxation, became calmer and received an increased feeling of harmony. Women felt happier and had increased patience when compared with before the treatment. In conjunction with the feeling of mental relaxation, they became more focused with mental acumen and experienced improved memory. Women described that they became uplifted and more creative through acupuncture treatment. When the feeling of energy was low, acupuncture gave additional energy, and when the feeling of stress was high, acupuncture gave calm energy.

I feel calm mentally and simultaneously I feel more mental energy and more focused, it's like my thoughts are clearer somehow, although I feel more relaxed. (Person 6)

Being able to live life to the fullest again. When migraine disappeared or was lessened by acupuncture treatment, women experienced that they got a new life or regained the life they had before with feelings of increased stability and freedom. Life was restricted to and ruled by migraine, but acupuncture gave stability to their lives and they dared to try more activities without being afraid of a migraine attack. Women expressed that they could enjoy more in life. It meant a sense of freedom when they did not need to think about what they could or could not do, and it was a liberating feeling to know that both family and work would not suffer. Women described how migraine affected the entire body; pain drained the body of energy and strength, qualities which acupuncture could restore. Women experienced that acupuncture gave physical strength, so they had more energy for activities.

I had been excluding the future in some ways, I had without seeing life in black or something, thought of me as living a life without the possibility to travel, without the potential to participate in courses, without being able to eat what I want, to never sleep in a morning, to live ever so structured and I had thought that would be my life, but it doesn't have to be so any longer. (Person 1)

It was experienced that acupuncture had resulted in a feeling of control over the effects of migraine. This manifested itself in a feeling of having the tools to control the migraine if it would become worse again. They described earlier warning signals of migraine, which made it possible for them to prevent the attack, by being able to take pharmaceuticals in time. Acupuncture also enabled the use of relaxation techniques and pharmaceuticals in abating migraine attacks. Women called attention to the feeling of safety they experienced when acupuncture worked. Before the treatment, pain was experienced as a paralysing symptom, which made the women unable to function during an attack, creating anxiety. They were no longer worried that migraine would attack them at any time.

Certainly it is control when you know that you can do something about it, it feels like a winning ticket, no money in the world can do anything about it, so it feels fantastic. (Person 2)

Discussion

The aim of this study was to describe experiences of acupuncture treatment among women with migraine. It shows that women experienced relief from pain and inconvenience in the body after acupuncture treatment. The relief not only involved the alleviation of migraine, but also the reduction in the use of pharmaceuticals and subsequent feelings of relaxation. The experience of alleviation in the effects of migraine is supported by Allais et al. (8) who found that acupuncture treatment for migraine both decreased the number of attacks and the intensity of pain. Acupuncture treatment can give prolonged alleviation from pain for patients with chronic headache, especially those who have migraine (5). By supplementing medical management with acupuncture, the combination improved health and the perception of patients that they suffered less from headaches, which was not seen in the group who received only medical management (16). In the study conducted by the authors, women had pharmaceutical treatments together with acupuncture treatment. Women experienced acupuncture treatment as different from medication treatment and believed it was more natural. Decreased use of medication was a valued effect. Acupuncture treatment can therefore be said to reduce the use of prescribed drugs (5,8,17). According to the result of this study, acupuncture could be one method of reducing the use of pharmaceuticals, which can be of great importance, as Bigal et al. (18) have noted that overuse of pharmaceuticals was a common reason for migraine developing into chronic daily headache.

After acupuncture treatment, among other things, women experienced increased mental comfort. The descriptions of an increase in energy and mental strength after acupuncture treatment, which included experiences of feeling increased mental calm, are similar to findings in another study of acupuncture users in the United States (11). Patients treated with acupuncture valued the increased general health in the shape of increased energy and well-being, together with reduced stress levels (17). According to Gould & MacPherson (19) acupuncture can affect emotional aspects of life. When energy is high and the feeling of well-being exists, it seems more likely that it is easier to handle pain and other health problems.

From the results, it was found that, when migraine disappeared or was lessened, the women were able to live life to the fullest. They described an increased freedom in being able to do things that earlier triggered migraine, which, in turn made it possible to have a better social life. Similar findings were reported in a group of patients with chronic daily

headache who experienced fewer limitations after acupuncture treatment (16). Migraine not only affects the woman's own life, it also affects family, work and social relations (4). Women in this study experienced a liberated feeling when they realized that family and work need not suffer because of migraine. To understand the importance of these findings, in the study of Ruiz de Velasco et al. (3), patients with migraine found it more difficult to see the family suffer as a result of their condition, than the symptom of the migraine itself, or the inability to work. Whether this is related with gender is a question that still needs to be answered.

The results of this study also showed that women experienced feelings of safety and control when acupuncture worked and migraine did not rule their life any more. They no longer needed to be worried about attacks of migraine appearing at anytime. The experience of safety and control over migraine resulting from acupuncture treatment, which emerged in this study, lacks support in other research, and therefore, this result must be treated with caution. This part of the result can arise from women in this study like the patients in the study by Belam et al. (10), who experienced a lack of control of living with migraine. When women in this study felt less and fewer symptoms and experienced that they have received an instrument that assists if there is an aggravation of migraine, it might be interpreted as an increased control over migraine, which earlier studies did not do.

Experiences during acupuncture treatment varied from very painful to no discomfort at all for women in this study. Griffiths & Taylor (20) obtained similar findings that the experience of the needle insertion varies from time to time and is different in different places on the body, and is different depending on who has administered the acupuncture treatment. Because pain and discomfort during acupuncture treatment might be grounds for patients to choose not to try or not to complete a period of acupuncture treatment, it is important to understand what is affecting these experiences during acupuncture treatment. Women who experienced pain and discomfort during the treatment described how it either depended on their own feelings of stress and tension, or on stressful surroundings. In the present study, both the experience as well as the outcome of the treatment was affected by women's opinion of the person who administered the acupuncture. According to So (21), the patient-therapist relation has greater impact on the outcome of acupuncture treatment when compared with the placebo effect. Patients' experience of empathy when they consult an acupuncturist is significantly correlated to patient empowerment, which in turn is highly correlated to

improved self-reported health outcomes (22). This brings to light the relationship between the person who administers acupuncture and the patient. According to Carlsson (23), a good patient-therapist relationship in acupuncture treatment can decrease anxiety and increase a feeling of well-being in the patient. The importance of the patient-therapist relationship in acupuncture treatment brings an uncertainty to the significance of acupuncture in the treatment of migraine. It raises questions about both the effect of acupuncture itself and the effect that a good patient-therapist relationship can have and the possibility that they both contribute by complementing each other into a better outcome. The need for more research within the area of acupuncture treatment is raised (21,22). The importance of using both qualitative and quantitative methods in future research is stipulated (21).

Methodological considerations

Although these results are based on a small sample, the material contained rich information and was, therefore, judged as sufficient for the aim of this study. The interviews with the women were conducted within the treatment period, which made it possible to obtain information about their experiences of acupuncture while they still remembered much in detail. Several of the women referred to earlier treatment periods and compared their experiences to the present treatment period, which made the material even richer.

With the support of Sandelovski (12), the narrative interview was chosen to support the participants narrating their own experiences. To increase trustworthiness, all the steps in the research process were described as clearly as possible and considered in the selected data collection and the data analysis method followed the selected analysis method (24). Representative quotations from the transcribed text were chosen to increase the credibility of the results. One of the authors, also the interviewer in this study, has knowledge and experience of treating migraine with acupuncture, which the other author did not have. This may reduce the chance that the result was coloured or narrowed down to one view only. Despite the results of this study having been influenced by the author's personal history and interest (25), it could be a basis for additional studies in the subject.

Conclusion

The results show that acupuncture seems to relieve pain, increase emotional strength and make it possible to live life to the fullest for women with

migraine, and hence physiotherapists are recommended to try acupuncture treatment for persons with this condition.

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