

Migraine and Emotion: A Qualitative Pilot Study

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Abstract

Migraine affects 10 per cent of the Australian population and may be severe in nature. To understand the subjective experience of migraine, five migraineurs were interviewed and asked to discuss the emotions associated with migraine. The negative emotional aspects associated with migraine, feeling socially supported and the belief of an external locus of control were the major themes that influenced the management and coping strategies of the participants. All experiences of migraine were negative. I suggest a greater emphasis on the emotional elements of migraine is required when educating students and practitioners about migraines, as there are strong emotional effects associated with this condition.

Key Words

Migraine, emotion, hopelessness, stress, locus of control, social support.

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Introduction

Migraine is derived from the Greek word meaning 'pain involving half of the head' (Murtagh, 1999). Migraine presents as a symptom complex of periodic attacks of vascular headache, usually temporal and unilateral in onset, commonly associated with irritability, nausea, vomiting, constipation, diarrhoea and often photophobia (fear of light). Attacks are preceded by constriction of the cranial arteries often with resultant prodromal sensory symptoms (Anderson, 2003). Physical, psychological and social functioning is markedly impaired during a migrainous episode (Cottrell, Drew, Waller, Holroyd, Brose, & O'Donnell, 2002).

Migraine is a condition that affects 10 per cent of the Australian population (Lipton, Stewart, Diamond, & Reed, 2001). Women are three times more susceptible to migraine than men with a life time prevalence of 18.2 per cent amongst females compared to 6.5 per cent amongst males (Heywood, Colgan & Coffey, 1998). Migraine is of great social and economic importance as it accounts for a large portion of work and school absenteeism. In 1990, the cost of migraine in Australia was calculated at approximately \$300-600 million per annum (due to absenteeism and reduced effectiveness at work) when the population was 18 million people (Parry, 1990). It can be assumed that as the population has risen by approximately three million people over the past fifteen years, the cost of migraine has also substantially risen in this time.

A variety of exogenous and endogenous factors have been identified as potential migraine triggers, with stress reported as the most culturally common trigger factor. Rates of stress-triggered migraines range from 17 per cent to 61 per cent (Martin, 1993). The reason for such a large variation may be due to the difficulty in defining and measuring stress. Over many years, several studies have investigated the link between stress and migraines, with each study bearing a variation on the definition of stress. Henryk-Gutt and Rees (1973) found that 54 per cent of migraine attacks coincided with emotional stress. Sorbi and Tellegen (1988) reported a significant correlation between normal everyday stress and occurrence of migraine attack. Another study reported no

indication of increased stress levels for days 2 and 3 before a migraine attack but elevated stress for the days immediately before and the days of the attack (Kohler & Haimler, 1990).

Social support, for example from family and friends, may play an important role in the way patients cope with migraines. Social support may be positive or negative. For example, if family members lack adequate information about migraine and have poor understanding of the patient's condition, a certain degree of frustration may result (de Valasco, Gonzalez, Etxeberria & Garcia-Monco, 2003). Loss of contact with friends and a variable degree of social isolation has been found to lead to sadness and a lack of understanding when assessing patients' social relationships (Cottrell et al., 2002). A study by Merikangas, Angst & Isler (1990) found the odds of migraine are 2.2 times greater in persons with depression than in those without depression. Several other studies have assessed the relationship of migraine with psychiatric morbidity and depression (Materazzo, 2000; Marazzitti, 1995), but I was interested in making a broader appraisal of the emotional aspects in relation to migraine.

The aim of this pilot study was to investigate the extent to which negative emotions (i.e. stress, anxiety) play a role in the development and management of migraines. I also aimed to explore the perceptions of social support within the migraineur's environment.

Method

Five participants (four females, one male) consented to partake in an individual semi-structured interview to explore the subjective nature of the experience of migraine. The ages of the participants ranged from 19-45 years. Their occupations were varied: a general practitioner, a bar tender, an osteopathy student, a law student and a graphic design student. Two participants were married and three were single. Advertisements were placed in the Victoria University Osteopathic Clinic and the participants were chosen via purposive sampling. Purposive sampling allows information rich-cases to be handpicked for in-depth analysis related to the central issues being studied. To be included, the participants must have experienced eight or more migraines over the past three years and met the International Headache Society (IHS) criteria for migraine. The IHS criteria involves the following (Murtagh, 1999):

- The person should have at least five of these headaches.
- The headaches last 4-72 hours.
- The headache must have at least two of the following:
 - (a) nausea and/or vomiting,
 - (b) photophobia and phonophobia.
- The headache must have at least two of the following:
 - (a) unilateral location,
 - (b) pulsing quality,
 - (c) moderate or severe intensity, inhibiting or prohibiting daily activities,
 - (d) headache worsened by routine physical activity.
- Secondary causes of headache are excluded (e.g. normal exam and/or imaging study).

An Information to Participant form (Appendix 1) was provided to all five participants and written consent (Appendix 2) was obtained prior to the interview. All participants were free to withdraw from the study at any time. This study received clearance from the Victoria University Faculty of Human Development Ethics Committee.

There was a very low rate of refusal to participate in this study as every person who was selected to participate consented to an interview. The questions in the interview addressed the emotional aspects before, during, and after a migrainous attack, and the current management procedures implemented by each person. The same semi-structured questions were asked in each interview and followed a basic format (Appendix 3). The interviews were conducted over the telephone. The discussions were tape-recorded, transcribed, and analysed for any themes and categories that arose during the discussions. Through this qualitative approach, I aimed to explore and understand situations, interpret phenomena and develop concepts in their natural context, with emphasis on meaning, significance and opinions of those taking part (Greenbaum, 1998). This methodology focused on the subjective aspects and personal experiences in individual lives, and is based on a small number of individuals, selected according to specific criteria (Denzin, 1994).

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Results

Analysis of my data revealed the emergence of an over-riding message – the impact of migraine on the participants' lives. The main themes that were found included:

- migraine as an emotional experience,
- feeling stressed and anxious,
- feeling migraines were outside of the participants' control,
- feelings associated with social support,
- self-helping behaviour, and
- the need to make sense of the problem.

The participants were not asked if any co-existing mood disorders were present and only one participant spoke about being depressed and taking anti-depressant medication.

The emotional experience

The impact migraines have at an emotional level is extremely relevant. Four participants spoke of desperation and frustration and a need for emotional control.

'One lasted for 4-5 days and I was just bawling and I had a little bit of an episode.'

'I feel cheated and pissed off ... it's like "ohhh, I've got another migraine.'

'I feel very fragile mentally and physically (when I have migraines). I am prone to get a bit emotional too like crying and I get very negative about myself.'

All participants reiterated feelings of hopelessness. Their powerlessness to fight the migraine once it had begun was echoed in their inability to do anything physically or mentally.

'I used to have to go and lie in bed all day. I couldn't really do anything.'

'I suppose I feel helpless because you just can't do anything.'

'My eyes go fuzzy, so then I can't drive. If I am stuck anywhere, I am stuck.'

'When I was really desperate...I would sneak into his (husband's) Valium as it was the only thing that would help me sleep.'

It is important to highlight the tone of emptiness and exhaustion the participants felt after a migraine and the need to re-fuel once their symptoms are over.

'I feel empty, completely empty after a migraine. I feel like I need to be filled up'.

'I feel drained and exhausted.'

'I feel worn out for a good 24 hours after a migraine. Like I am not all there...a bit vague. I can't concentrate.'

Feeling stressed and anxious

All participants suggested stress, either mental or physical, was a trigger for migraines.

'I get migraines when I get run down and stressed and a lot of the time when things get quite demanding.'

'There is no way I handle stress well, but I am still learning. I am hopeless.'

'My stress levels are pretty low. I am pretty calm most of the time but I get migraines when I play lots of sport which is physically stressful on my body.'

'I get more anxious about getting stressed then being apprehensive about getting a migraine.'

Locus of control

There was a recurrent reference to the need to assume control over emotions, stress or the presence of migraines. Most participants mentioned anxiety playing a role in triggering their migraines. They also expressed feelings of anxiety on non-migraine days when thinking about when the next one would 'strike'. It appears some participants felt they were controlled by the migraine.

'It used to be helpless but now I am taking control...I am trying to accept that it is part of my life. I just don't want to have them anymore.'

'I get anxious when I have got something really important going on and I might start to get funny vision.'

'I don't think anyone would judge me for something I can't plan.'

Feeling socially supported

With regard to social aspects, three different areas covering the participants social life were considered: (i) work and studies; (ii) life within the family and/or with a partner; and (iii) social relationships outside the family and working environment.

Work and Studies

One of the most frequently mentioned aspects was activity at work and university. All participants reported that it was difficult to continue daily activities, such as work or study. Two sub-themes emerged here: the participants' ability to cope at work with migraines and the support they received from other people in their work or university environment.

Coping at work:

Two participants were able to go home and rest when they had migraines.

'Work was always really supportive. If you are not well, you're not well. Maybe if I had to go home all the time, it might have been different.'

'Considering my boss has never had a sick day in eighteen years, she is really good. She would tell me to go home'.

The other participants continued working because of financial reasons or the inconvenience caused to others.

'I would go to work because I needed the money but I would dose up on Neurofen or something like that. I just had to push on.'

'The worst time I get them is at work. I am a GP so I can't just say bye to work.'

A sense of high self-expectation is seen here. In her own clinic she would send her patients with migraine home to bed and distribute medical certificates for work absenteeism, however, she does not do the same for herself.

Support from those in the work/university environment:

The two participants who were at university did not receive much personal support in this environment, whether it was expected or otherwise.

'I had to get special consideration one semester. But at university they don't really know you. You are just a faceless number: a blob of HECS. I have never really considered having any support from university.'

'My studio subject teacher wasn't terribly understanding as I would need to take a night off to get rid of a migraine.'

There was a mixed view regarding whether the participants received support from those around them at work.

'A lot of people at work don't know what a migraine is, they just think it is a headache. They think you are a wuss.'

'I would say my colleagues are very supportive as some of them get migraines too.'

This quote blends into a social support theme. It seems that there is a high degree of empathy shared between migraineurs.

Family Relationships

All participants reported positive support from family members, whether it from spouses or parents. The impact of migraine extends beyond the individual to family if they have to perform extra duties within the family circle when the migraine sufferer simply cannot physically perform those tasks.

'My husband is good. He knows that when I need to sleep, that's it...he'll make sure my toddler son is out of the way.'

'My husband is wonderful...he does everything for me. I feel like I have got heaps of support and they are really getting much, much better.'

'My mum...suffers migraines too and knows what they are like when they are really bad...she can relate and understand that they are quite debilitating.'

However, some participants also reported that family relations were the cause of stress, therefore a trigger of their migraines.

'I need to accept my family, knowing that I can't change any of them or the way I respond to them.'

'With my family, things can get so complex and so deep and it is hard to really overcome them or really understand the strangle-hold that parents have over your life.'

'Some kind of ongoing stress like extra pressure at work, or some kind of strain with my husband or problems with my child.'

'Issues with my parents because they are divorced...I have to juggle that and it can be an issue for me.'

Social Relationships

When commenting on their social settings, examples were given of how the social climate of the participant was affected by migraine.

'I can't go out every weekend and have a few drinks. I am concerned I will get to 30 and will not have experienced my 20s. It's frustrating and I do get upset.'

'Living on my own made me a much more inward looking person. That is when my migraines started.'

'I definitely receive enough support. I am not looking for anymore.'

In analysing this final statement, I suggest that social support can sometimes be problematic for this person, although she is not admitting it explicitly. It may be interpreted that she has enough friends; she is not looking for anymore. More friends would mean she would have to work harder at more relationships.

Do they feel there is a stigma attached to their migraines? Their opinions were mixed.

'I don't feel there is a stigma attached. I don't feel anyone would judge me for something I can't plan.'

'I definitely think there is a stigma attached to migraines; mainly due to other people's ignorance.'

When present, stigmatisation was most obvious within the workplace. People are motivated to avoid the sick role as they wish to be perceived as strong or able to cope. However, if they could not keep up appearances, some felt they were judged or marginalised.

Help-seeking behaviour

All the participants spoke about various health care treatments they had sought in either trying to combat stress or migraines. These interventions ranged from complimentary therapy to mainstream, orthodox medicine.

'Shiatsu whenever I feel like I am tensing up.'

'Regular osteopathy appointments have been an important strategy in managing migraines.'

'The main people to have helped me are my mum, my neurologist and psychologist.'

'The GP said I put way too much pressure on myself. She told me to take it easy. She put it back on me which is a good idea, but it takes a while to take responsibility for stuff.'

This final quote also addresses the locus of control theme. This person admits taking responsibility for the pressure she puts on herself was not easy to accept. All of the participants reported these therapeutic interventions helped them cope with their migraines.

Making sense of the problem

There was a need to understand what was happening and to place the problem in the context of their lives. Some participants attempted to make sense within a physical framework. Three of the four female participants associated menstruation with the onset of migraine.

'I get a migraine when I relax after I have been really stressed...usually it will be a day after exams.'

'For a year, I always had migraines on a Monday.'

'Usually when I get my period, they get terribly bad'.

In summary, the most frequently discussed themes included the emotional experience of migraine and the stress and helplessness associated with the condition. Each participant spoke about their experience of migraine in the home, work place and social setting and each had varying degrees of societal support.

Discussion

In this study, I describe the influences of migraine on patients' life using qualitative methodology, thus providing an exploratory and discovery orientated perspective. My results indicate that negative emotions play a substantial role in the experience of migraines. The impact of migraines on quality of life has been well documented (Cottrell et al., 2002). My results reinforce the effects on quality of life that migraine represents for patients and, in this way, agree with previous quantitative studies. Other studies have shown physical and psychological impairment occurs during attacks, resulting in the inability to perform normal job or role functions (de Valasco et al., 2003). This research shows some people report strong emotional effects related to their migraine experience. It cannot be said, however, that it confirms other studies findings relating to the psychological impairment during migraines. This is due to the small sample size and the type of research design, in that it only allowed the reporting of emotional responses, not measurements of the effects.

All participants spoke freely about the pain, functional disability and management problems associated with migraines, however it appeared the associated emotional aspects were secondary. The only male participant denied emotional distress, however all the women integrated negative emotional descriptions into their discussion. Possibly people are inclined to emphasise pain and disability but minimise emotional reactions in an effort to legitimise frequent migraines as a serious medical problem.

Several theoretical explanations of the psychosocial factors that influence healthy and unhealthy behaviour have been outlined in the literature. The concept of health locus of control is one theory that suggests individuals differ as to whether they tend to regard events as controllable by them (internal locus of control) or uncontrolled by them (external locus of control). One of the predictions to emerge from the health locus of control model is that people with a high internal locus of control will engage in health-promoting activities, whereas the reverse will be true of those with strong beliefs in chance (i.e. high external locus of control; Johnson, 2004).

There appears to be a contradiction in the participants' beliefs that emotional control would prevent migraines while simultaneously viewing the health locus of control as external to their bodies. All the participants suggested some form of stress, either physical or, more commonly, mental, played a role in the development of their migraines. Overall, the participants had a low health locus of control, as they labelled stress as an exogenous migraine trigger, rather than an endogenous factor over which they had any kind of power. The experience of migraine was referred to as a malign and external occurrence. All participants spoke of an anxiety regarding when the next migraine would 'hit' or 'strike'. They spoke of 'the' migraine, rather than 'my' migraine. Some participants said that control is the key to managing their stress levels and emotional states and a loss of control inevitably resulted in migraine. These themes are consistent with other literature studies (de Valasco et al., 2003)

All participants were actively seeking help for their migraines through different avenues, including both orthodox and complementary approaches. Physical therapy was a key management choice discussed by the participants and it can be divided into two types: active therapies in which the client takes a driving role, and passive therapies in which the therapy cannot proceed unless driven by a therapist (Cameron, 2004). Active therapies require the patient to be a partner in care, not just a recipient of care. Exercise is a form of active therapy whilst massage, shiatsu and osteopathy are all considered to be passive therapies. Only some of the participants engaged in active therapy to help manage their symptoms of stress, however all engaged in passive therapy. It would seem they sought out health professionals to assist them manage health problems related to lifestyle. Again, this reinforces the view that the individual cannot control migraines due to the sub-conscious belief that migraines are not controlled internally; rather, 'it' was a malignant entity beyond their control.

Regarding social aspects, efficiency at work and university were frequently mentioned as being severely undermined by migraine. Participants agreed that migraines were worst in the working environment. The need to 'push on' resonated throughout the interviews. The coping process involves managing the perceived discrepancy (migraine) and the

demands of a situation (work) with the available personal and social resources (emotion/behaviour). As discussed by Wiese-Bjornstal (2004), personality and dispositional tendencies influence the psychological adaptation to the experience of illness. Individual traits determine whether the participant 'pushed on' at work (unhealthy maladjustment to the migraine) or left work to rest (healthy adjustment to the migraine). Coping strategies are not inherently adaptive or maladaptive, but their effectiveness varies depending on the individual and the situation (Wiese-Bjornstal, 2004). Within a clinical situation, one area of intervention is the identification of irrational beliefs about the effectiveness of certain coping techniques. Coping strategies can be adjusted to the individual client, therefore the client becomes an active collaborator, which results in greater perceptions of control.

Stigmatisation was an issue for some participants in the work place. The person who occupies the sick role is vulnerable to societal abuse and marginalisation. They may be stigmatised and seen as someone who is other, who is judged differently from healthy people in ways that are judged as inferior (Mitchell & Cormick, 1998). The participants who denied the presence of stigma are either: completely surrounded by compassionate, empathetic people, or not seen publicly as unable to cope. Perhaps they have a combination of both: a network of caring people around them, plus the ability to keep up appearances in public.

The notion of 'keeping up appearances' was echoed throughout the interviews. People are motivated to avoid the sick role as they wish to be perceived as strong or able to cope. They do not want to be kept in a disadvantaged position without the opportunity to develop social power or choices, without access to material or economic resources (Mitchell et al., 1998). Moreover, the care they receive from others may not be the loving and empathetic sort of care one would hope to receive.

The adoption of the sick role can convey some benefits: avoidance of responsibility, continuation of protection and dependence, access to care and attention (Mitchell et al., 1998). These concessions were most obvious within the family environment. All

participants reported positive support from family, whether it from spouses or parents. The impact of migraine extends beyond the individual to the family if they have to perform extra duties within the family unit when the migraine sufferer physically cannot perform those tasks. The greatest understanding and empathy came from mothers of participants who also experienced migraines. However, for some participants, family interaction was also considered to have a negative impact and associated with stress that subsequently triggered migraines. Emotional control and acceptance of family were the underlying features here and restate the point of an external locus of control causing the migraines.

Loss of contact with friends and a variable degree of social isolation were also consequences mentioned by most participants. These are factors that harm psychological wellbeing and increase the risk of depression. All the participants pointed to major changes in their mood, mainly in the form of high levels of negativity, sadness and frustration. A lack of understanding was found, which was also the main feeling described by Cottrell et al. (2002) when assessing participant's social relationships. One patient described the lack of understanding as 'ignorance' that contributed towards the stigma attached to migraine sufferers.

Social support provides morale-enhancing experiences until the sick person regains his/her own strength. Frank (1973) describes the way in which ill people become demoralised: in terms of the psychological aspects of the illness, they lose confidence, they do not feel capable of dealing with further aspects of their lives and they may experience shame, guilt and helplessness. Because of the physical aspects of the illness, they lose the capacity and energy to manage their own lives. There is a relief, for the patient, in finding someone who will join him/her in the struggle.

A major component in positive social relationships is the giving and receiving of care. One participant spoke of not needing any further support than what was currently available to her. It seems social support may have been problematic to her in the past. Instigating new relationships requires the investment of emotions into an unfamiliar

person. Perhaps she does not want to expend the effort and emotion on developing new social supports because they may be unsuccessful or fruitless.

There was a need to understand what was happening and to place the migraines in the context of the participants' lives. Some participants attempted to make sense within a physical framework, while others were struggling for a meaning. Belam et al. (2005) suggested that as human we look for patterns in the experience of our lives, searching for relationships and regularities. Some participants created meaning within a physical framework of the cause and effect while others were still searching for meaning.

It is important to note this study's limitations. The interview format is an effective method for soliciting issues of greatest importance to the individuals who participated, but it does not provide information on the prevalence of those opinions in the population. The information provided in the interviews may have been influenced by the fact that individuals who volunteer to participate are likely to have different views from those who do not participate in such research. Obviously, the participants were willing to talk about their migraines. Possibly, people who did not wish to be interviewed are more private about their migraines or concerned about projecting an image of coping with and managing their condition. However, the rate of refusal to participate in this study was low. It was not determined when participants last experienced a migraine, therefore it is difficult to know how much recall bias is inherent in this study.

The small sample size limits the ability to generalise about the findings. Thus, the experiences and views reported cannot be considered representative of all migraine sufferers. Five participants were included in the study, however only one male was interviewed. Although this is an approximate gender ratio split in the population of migraineurs, it may have some bearing on the results, as women are more likely to seek health-related assistance and express emotive responses. In this study it would seem that the female participants were willing to express emotions more freely than the only male participant, however it is difficult to base this assumption on one man's responses in the interview.

Unlike classical quantitative studies on quality of life, qualitative studies such as this add information about the subjective nature of the migraine experience. Different feelings and perceptions of migraineurs help to enrich clinical practice, enabling the practitioner to understand the patient's experiences and needs. The use of discovery-orientated methodology in the assessment of migraine patients not only allows appraisal of the impact of migraine, but also opens up new areas for future research. Further studies should compare the effectiveness of stress management (through active versus passive therapies) to determine whether this has an impact on their migraine experience. Other future studies could look at the association between mood disorders, i.e. depression and migraine.

In summary, this research identifies the need to acknowledge the strong emotional responses to the experience of migraine. This may play a role in helping to identify the triggers that offset a migraine episode. This study also provides an insight into how people manage migraines and the changes they make to help deal with their symptoms. By highlighting both healthy and unhealthy coping strategies that can be adopted in the face of a migraine episode, it is hoped that therapists are able to educate their patients about the benefits of positive adjustment when occupying the sick role.

Conclusion

The International Association of the Study of Pain describe pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (Merskey & Bogduk, 1994, p. 210). As holistic practitioners, it is imperative to place equal emphasis on both the physical and emotional elements of the migraine experience. As migraines are so prevalent and have such social, economical and personal ramifications, it is essential that practitioners be equipped to manage and treat effectively. It is important to educate sufferers to ensure they have an active role in managing the lifestyle factors that affect their migraines. In understanding the painful and personal experiences of migraine, it is hoped there will be an increased awareness to create an environment where sufferers can speak openly about their experiences of migraine.

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