

Not Just a Headache: An Interpretative Phenomenological Analysis of the Lived Experience of Hemiplegic Migraine



Dr Anna Marie Dowling^{1,2}, Dr Jonathan Egan²

1. Psychology Team, Mayo Mental Health Service, HSE West. 2. School of Psychology, NUI Galway



O'É Gaillimh
NUI Galway

Introduction

Hemiplegic migraine is a rare type of migraine with aura involving motor weakness and at least one other aura symptom. Many of the symptoms mimic those of stroke. There are two types- familial and sporadic. The estimated prevalence is 0.01% (Thomson et al., 2002) but may be higher (Moore et al., 2019). Female to male ratio is 3:1 (Thomson et al., 2002). Research has focused on the medical aspects with no identified prior studies on the subjective experiences of those living with the condition.

Aim of Investigation

Aim: To explore the subjective experiences of women living with a diagnosis of hemiplegic migraine.

Results

Theme 1: "What is it?"- Making sense of hemiplegic migraine

Hemiplegic migraine is experienced as a poorly understood and under recognised condition even among healthcare professionals. Feeling dismissed was a common experience among participants.

Theme 2: "Taken its toll"- The price of hemiplegic migraine

Hemiplegic migraine had an significant emotional impact, negatively affecting sense of self, relationships and engagement in everyday activities. Some felt that life with hemiplegic migraine was no life. Living with the unpredictability of the disorder was particularly problematic.

Theme 3: "Deal with it?"- Finding ways to cope with hemiplegic migraine

Participants employed a variety of methods to minimise both the risk of an attack and the impact of those that occurred. Psychological therapy, family support and spending time in nature and with animals were considered lifelines for coping. Acceptance and hope are also important.

Methods

Ethical Approval: Granted by the NUI Galway Research Ethics Committee on 18/05/18.

Design: Cross sectional qualitative design.

Participants: Selected by purposive sampling. The Migraine Association of Ireland was the primary recruitment source. All 8 participants were female (23-54 years) and lived in the Republic of Ireland.

Materials: In-depth semi-structured interviews carried out between 19th Oct-7th Dec 2018. Average duration 44 ½ minutes. All interviews were audio-recorded.

Analysis: Interviews were transcribed, uploaded to NVivo 12 and analysed using Interpretative Phenomenological Analysis.

"My speech was going. I couldn't remember simple things. My head was pounding. My arm was killing me. My face was killing me and I just, I wasn't able to function properly" "I just went into my mam and I was like "I can't feel my face. I can't feel my arm. Something is really wrong"

"Instead of saying 'Let's investigate more ways to help you', they dismiss you"

"You know it's coming. It's like a time bomb. It's looming there somewhere"

"For doctors who don't specialise in neurology or migraine they haven't a clue. They haven't a clue"

"People who don't get migraine don't get it. They think it's a bad headache"

"Like even as I sit here, I'm terrified what's going to come on me"

"You don't feel like a person anymore"

"So I've felt a massive burden my whole life with migraine and what its brought"

"I'm not really living"

"I've missed a lot of family events. I've lost a lot of friends. I haven't been able to keep to commitments"

"You always have a backup plan"

"Without therapy I don't think I'd be alive today"

"But I'm trying not to get too anxious because I'm aware that anxiety and stress does feed into, feed into all that"

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Conclusion

This study highlights the need for increased education and awareness in relation to the condition. Addressing the emotional impact of hemiplegic migraine needs to be considered in treatment planning.

References 1. Thomsen, L. L., Eriksen, M.K., Romer, S.F., Andersen, I., Ostergaard, E., Keiding, N., Olesen, J., & Russell, M. (2002). An epidemiological survey of hemiplegic migraine. *Cephalalgia*, 22(5), 361-375. doi:10.1046/j.1468-2982.2002.00371. 2. Moore, B.A., Hale, W.J., Nabity, P.S., Koehn, T.R., McGeary, D., & Peterson, A.L. (2019). A retrospective, epidemiological review of hemiplegic migraines in a military population. *Military Medicine*, usz040, doi: 10.1093/milmed/usz040.