

The "I" in Fibromyalgia: How does Fibromyalgia Shape Academic Identity?

What is fibromyalgia?

Fibromyalgia is a complex, invisible illness of unknown cause that is characterised by chronic, wide-spread pain, fatigue, sleep disturbances, cognitive dysfunctions, increased sensitivity and psychological disorders (White and Harth, 2001). It is also closely linked with other diagnoses such as chronic fatigue syndrome (Yunus, 2008). Globally, between 0.66% and 10.5% of the general population suffer from fibromyalgia (Queiroz, 2013).

References:

Queiroz, L. P. (2013). Worldwide epidemiology of fibromyalgia. *Current Pain and Headache Reports*, 17, 356.

White, K., & Harth, M. (2001). Classification, epidemiology, and natural history of fibromyalgia. *Current Pain and Headache Reports*, 5, 320-329.

Yunus, M. (2008). Central sensitivity syndromes: A new paradigm and group nosology for fibromyalgia and overlapping conditions, and the related issue of disease versus illness. *Seminars in Arthritis and Rheumatism*, 37, 339-352.

Why do I research fibromyalgia amongst academics?

Most research into fibromyalgia only considers the pain aspects of the syndrome rather than fibromyalgia in all its facets. There is no research focussing on academic sufferers although high prevalence of chronic fatigue syndrome has been confirmed amongst students, teachers and medical staff.

What are the aims of this research?

...to explore how academics make sense of and experience their lives whilst suffering from fibromyalgia

...to investigate which coping strategies academics employ

...to uncover how fibromyalgia with all its symptoms may or may not impact academics' private and public selves

How will I collect data?

Identity boxes: Metaphors and visuals are used for specific representations. Participants are asked to fill a container with their chosen items in response to specific questions.

Timelines, critical incidents and diary extracts: These allow for a holistic insight into the academic's life-story.

Making representations: Research participants collaborate on making representations of life with fibromyalgia. These representations could be paintings, collages, installations, photographic projects, simulations, poetries, plays.

Discussions and interviews: As metaphors and representations require interpretation, conversations are used to ensure the interpretations are truthful and meaningful.

Why use identity boxes and representations?

Within pain and illness experiences it is acknowledged that words are often imprecise and fail to express reality and truth (Scarry, 1985). Also, the complexity and variability of fibromyalgia with its changeability of symptoms and the levels of severity require a holistic, corporeal, non-verbal approach in addition to more traditional interviewing techniques.

References:

Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. Oxford: Oxford University Press.



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Scan the code for more information about the research and to watch simulations of what fibromyalgia feels like.



Research aim:

The research will explore how academics make sense of their experiences whilst suffering from fibromyalgia and its many symptoms. The research will investigate how academics live with fibromyalgia, which coping strategies they employ, how these coping strategies may or not may not impact the private and public selves and how traditional fibromyalgia treatment routes are experienced. Finally, the research will consider issues around disclosure/non-disclosure and stigma surrounding the invisible illness fibromyalgia.

Framework for participation:

Participation in this research is entirely voluntary and participants may withdraw at any point without giving reasons. The research question will be investigated through the use of creative methods, which will require participations in interviews, online discussions and creative and creating activities.

Timeframe for the research:

The research will run in different phases.

One group of participants will take part in research activities from January 2017 to September 2017, and the second group will undertake activities from January 2017 to July 2018.

Most of the activities and tasks participants will get involved in, will be carried out in their own time and in the comfort of their own homes. There will be group meetings and interviews, which will be scheduled as face-to-face or online sessions depending on circumstances and availabilities.

Benefits of taking part in the research:

There is no financial or material reward and there may not be any immediate benefit for the participants in this research. However, it is anticipated that the research will lead to better understanding of the process of making sense of and coming to terms with the fibromyalgia diagnosis and treatment. It is also hoped that as a result of this project fibromyalgia treatment options may be changed to reflect this process.

Potential disadvantages of taking part in the research:

Due to the nature of the research into experiences with fibromyalgia participants may at times feel uncomfortable reflecting on these feelings. Participants will not ever be asked to share anything that they do not feel comfortable sharing, and they can skip questions at all times without giving reasons. Throughout the research participants will be involved in the meaning-making process in that any sections of analyses will be shared for clarification and information purposes. At this stage participants may ask for any statements to be withdrawn or not used in the final write-up of the research.

Findings:

Findings of this research will be shared at relevant conferences, in academic journals, in the final written doctoral thesis. Findings will also be shared with relevant policymakers, fibromyalgia treatment and pain management providers, and for information purposes with fibromyalgia support networks and the general public. A summarised preliminary report of the findings will be shared with all research participants.

If you are interested in finding out more about this research or if you know of someone else who may do, please, contact me at nicole.brown@ucl.ac.uk