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## Service users' and service providers' views and experiences of fibromyalgia in the UK and Libya

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**Background:** Chronic widespread pain conditions such as fibromyalgia syndrome are prevalent and costly to the economy. Diagnosis is based upon symptoms and although its existence as a distinct clinical entity is debated, it causes great suffering and distress for those affected. Due to the unclear pathophysiology, controversy regarding its existence as a clinical entity, and also variability in diagnosis, clinical management is often difficult and frequently employs heterogeneous interventions. There is a paucity of literature from Middle Eastern countries, where the diagnostic label is not used.

**Objectives:** The purpose of this research study is to capture service users' and service providers' views and experiences of fibromyalgia and its management including their views of the journey to diagnosis, current practice and availability, emotional and lived experience, information seeking and experiences of seeking and receiving health care. It also aims to describe current practice for fibromyalgia in the UK compared with Libyan management procedures for chronic widespread pain.

**Methods:** A mixed methods approach using a convergent parallel design was used in a two phase study. Phase one consisted of 12 semi-structured interviews conducted with people diagnosed with Fibromyalgia (FMS). Participants also completed the Fibromyalgia Impact Questionnaire (FIQ) and Toronto Alexithymia Scale (TAS). Phase two consisted of a national survey of health and medical professionals from the British Pain Society and medical professionals in Libya regarding their views and management practices of fibromyalgia. Findings were synthesized with qualitative findings.

Results: Using framework analysis, the following themes were identified from the qualitative study; the journey to diagnosis, coping with varying and unpredictable nature of symptoms, emotional impact and availability and satisfaction with healthcare practices and services. The primary qualitative study highlighted some difficulties participants faced regarding a perceived lack of understanding by health and medical professionals and also the general public regarding management of the condition and the emotional and physical impact of FMS. These findings suggested people were not managing daily living activities due to disabling fatigue and worsening pain. This was corroborated by high FIQ scores and high alexithymia scores. This part of the study illustrated that a variety of intervention approaches are used with varying and often limited success. A total of n=69 respondents completed the survey. Results indicated that increasing numbers of people are diagnosed with fibromyalgia though a range of differing diagnostic labels are used. Treatment approaches in both countries were primarily focused upon exercise and education, with CBT being used in the UK. Respondents from both countries agreed there was a strong psychological overlay, though there was a statistically significant difference between opinions regarding whether active management approaches should aggravate pain temporarily in order to achieve functional gains (p<0.05).

**Conclusion:** The results indicate the high physical and emotional impact of fibromyalgia. Participants' perspectives have illuminated the need for support for people living with FMS and the need for education and standardization of approaches in clinical practice in both the UK and Libya.

## **Biography**

Sedik's interest in chronic pain and musculoskeletal disorders began as he was nearing the end of his BSc in physiotherapy, obtained from Nasser University, Libya. His dissertation was titled acupuncture approach for the management of chronic low back pain. He then continued his studies to in the UK, at North Umbria where he undertook a systematic review into the management of chronic low back pain for the completion of his MSc. Following this in 2005, he proceeded to work in the Libyan health Authority public sector for 10 years in musculoskeletal interventions. In 2007, he also began work as a physiotherapy lecturer in Libya and endeavored to teach physiotherapy elements, practice and neuro-management

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