No one wants to look after the fibro patient’. Designing effective healthcare services for patients with fibromyalgia: two systematic reviews.

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EBASE, AMED, CINAHL, PsycINFO, Web of Science, and Cochrane CENTRAL were searched in January 2018.

Reference/citations lists (n = 2)

Studies included (n = 19)

Figure 2 – PRISMA flow chart

Patient care experiences and perspectives

From 8,268 identified records, 19 studies (quantitative, qualitative, and mixed methods) were eligible (Figure 2).

Background

- Fibromyalgia is a common and complex long-term pain condition.
- Patients with fibromyalgia report difficult healthcare journeys, resulting in feelings of frustration and disregard.
- It is unclear how best to organise and deliver healthcare across the healthcare system.

Aim

To examine existing evidence on a) models of care for fibromyalgia and b) patients’ care experiences, preferences for care and unmet needs.

Methods

- Two systematic searches were undertaken.
- A model of care was defined as evidence-informed framework guiding best care delivery across the entire healthcare system. The second search focused on patients’ experiences and views on aspects such as care settings, care processes, and responsiveness of healthcare providers.
- MEDLINE(R) Ovid, EMBASE, AMED, CINAHL, PsycINFO, Web of Science, and Cochrane CENTRAL were searched in January 2018.
- Reference and citations lists were also screened.
- Quantitative data was narratively and qualitative data was thematically synthesised.

Results

Model of care

- From 1,535 identified records, six studies (all quantitative) were eligible (Figure 1).

Figure 1 – PRISMA flow chart

- Limited evidence suggests no clear benefit for ongoing care in secondary care settings.

- Delays in diagnosis and exhaustive visits to numerous healthcare providers were common.
- Lack of continuity and coordination of care by healthcare providers concerned patients.
- Difficult interactions with healthcare staff (such as disbelief and mistrust) appeared to dominate.
- Access to appropriate, ongoing care was often limited, affecting thereby patients’ ability to self-manage their condition pro-actively.
- Patients with positive care experiences felt better informed, well supported, and more satisfied.

Conclusions

- Overall healthcare provision is inconsistent and poorly coordinated, with important patient needs not being met. Patients with fibromyalgia currently miss out on timely, appropriate, and continuous care.
- Patient care preferences are unknown at large.
- The findings provide a strong rationale for developing a new model of care for fibromyalgia.

Relevance for patient care

- Understanding patient experiences and journeys through the healthcare system is essential to inform improvements in care.

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