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Chronicity rhetoric in health and welfare systems inhibits patient recovery: a qualitative, ethnographic study of fibromyalgia care

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ABSTRACT

Fibromyalgia is a leading cause of disability in the UK and worldwide, but is difficult to diagnose and treat due to unclear pathogenesis and diverse and fluctuating symptoms. Although various treatment modalities are recommended, no treatments have been proven to effect sustainable improvement or recovery, and patients are typically dissatisfied with their care. Increasingly, biopsychosocial services are being developed, that aim to take a multifaceted, holistic approach. In this paper, we draw on a qualitative, ethnographic study of biopsychosocial services in the UK (including 59 interviews, 200 h observation, document review, and stakeholder workshops), that are providing new and promising forms of support. Drawing on Smith's Sociology for People as our analytic framework, we explore the work that is undertaken in these services. We discover chronicity rhetoric that interrupts practitioners' and patients' efforts to promote healing and recovery. We show that chronicity rhetoric is produced and reinforced through Biomedical Research and Welfare Benefits systems. Our findings are likely to have wider applicability to services for other difficult-to-treat conditions that are having increasingly problematic impacts on health, wellbeing and economic productivity worldwide (e.g., chronic pain, Chronic Fatigue Syndrome (CFS), Myalgic Encephalomyelitis (ME)).

1. Introduction

Fibromyalgia syndrome is a condition characterised by persistent and widespread pain that is associated with intrusive fatigue, sleep disturbance, impaired cognitive and physical function and psychological distress. It is classified in the International Classification of Diseases ICD-11 as Chronic Primary Pain. (Royal College of Physicians, 2022)

Fibromyalgia is estimated to affect 1.2–5.4 % of the UK population, depending on the definition employed (Creed, 2020), and is a leading cause of disability worldwide (Häuser et al., 2015). However, it can be challenging to diagnose as patients report a wide range of fluctuating symptoms, which partly overlap with other musculoskeletal conditions. Treatments are only moderately successful, and its pathogenesis incompletely understood (Dennis et al., 2013; Borchers and Gershwin, 2015; Royal College of Physicians, 2022). There have been significant advances in scientific understanding of the condition as new investigative technologies have been developed (Abeles et al., 2007; Clauw, 2009). Established treatments include physical therapy, psychological therapies, pharmacotherapy, and multi-modal rehabilitation programmes (Borchers and Gershwin, 2015)—which should, according to management recommendations, be tailored to the individual (Macfarlane et al., 2017). However, service provision for people with fibromyalgia varies considerably across the UK, and patients are typically dissatisfied with their care—consistently complaining that they are bounced from one specialty to another as part of an often long diagnostic journey, or in a fruitless search for effective treatment (Doebl et al., 2020). Many people therefore seek help outside conventional healthcare services (Mengshoel et al., 2018), particularly from complementary and/or alternative therapists (Arthritis Research UK, 2012).

In this paper, we draw on a qualitative, ethnographic investigation of services for people with fibromyalgia, being developed and delivered in the UK. This investigation was undertaken as part of the PACFiND study (Patient Centred Care for Fibromyalgia: New Pathway Design) (Macfarlane, 2021), and focused on twelve case studies. Each involved innovators with a special interest in chronic pain and/or fibromyalgia, and were typically defined as "biopsychosocial" services (Engel, 1981)—in contrast to established biomedical care. All orientated around

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general principles of holism (Shroff, 2011) and employed mechanistic explanations such as Central Sensitisation as the basis for treatments to dampen down the nervous system (Gatchel and Neblett, 2018). For simplicity, we mirror participants' use of the term "biopsychosocial", whilst also acknowledging ongoing debate about its specificity and usefulness (Borrell-Carrió et al., 2004).

We employ Smith's (1987, 1990, 2005, 2006) Sociology for People, and specifically her (2003) concept of *work*, to make visible the healing work that is undertaken collaboratively by practitioners and patients within biopsychosocial services (see also Davis and Gonzalez's (2016) comparison of *fixing* with *healing*). Healing work provides a place to begin in the "actualities of people's experience" (Smith, 2006), taking into consideration the visible and taken for granted—"everything that is involved in *doing* the work" of healing (Smith, 2003). We focus on the experiences of practitioners supporting people with fibromyalgia. However, we recognise that the work of *practitioners* is intertwined with that of *people with fibromyalgia*, who actually have to implement solutions in everyday life. It is in the lives and bodies of people with fibromyalgia that healing actually happens, and so we also bring into view the experiences of people with fibromyalgia through the accounts of practitioners who work collaboratively with them. Our analysis is informed by literature on patient experiences of fibromyalgia (Author et al., forthcoming), patient experiences of services captured in the wider PACFiND study, and dialogue with Patient and Public Involvement and Engagement (PPIE) representatives throughout the study.

We focus on representations of fibromyalgia as a "chronic condition", which infiltrate and disrupt healing work. Using Smith's analytic lens, chronicity is a textual representation that organises both knowledge and practice relating to fibromyalgia care. People activate concepts of chronicity that are available to them, in ways that are responsive to their own situated context and needs (Smith and Turner, 2014). We show that it is in the interests of many actors (e.g., researchers, patients) to adopt representations of fibromyalgia as a relatively stable and predictably chronic (albeit fluctuating) illness (Singer and Jack, 2020). Using Smith's approach, the disjuncture between healing work and representations of chronicity provides a place to begin—from which to shine a light into the institutional infrastructure. We present examples showing how chronicity rhetoric arises from two apparently separate institutional domains (Biomedical Research and the Welfare Benefits system) and coalesces to inhibit the healing work of practitioners and patients. Such attention to the *social organisation* of healthcare systems is of crucial importance to understanding and improving healthcare delivery, and is too often overlooked (Griffiths, 2003).

2. Methodology

A multi-site ethnography involving twelve case studies drawn from services for people with fibromyalgia across England, Wales and Scotland was conducted during 2021–2023. This work was part of a larger study, PACFiND (Patient Centred Care for Fibromyalgia: New Pathway Design), which also included patient experience research (Doebl et al., 2020, 2022) and surveys to map current service provision (Wilson et al., 2022). The study received ethics and research governance approvals (IRAS ID: 275725).

Twelve case studies were recruited through professional networks and online searches. The researchers proactively worked to ensure that there was representation across England (n = 5), Scotland (n = 3) and Wales (n = 4). Criteria for inclusion were that sites delivered services to people with fibromyalgia, were located in England, Scotland, or Wales, and were willing/able to facilitate research access. We did not apply any exclusion criteria. Participating services were led by practitioners actively working to improve the care of people with chronic pain and/or fibromyalgia (from a variety of professional backgrounds e.g., medicine, psychology, physiotherapy). All services were self-described as "biopsychosocial" (Engel, 1981)—or similarly underpinned by principles of holism (Shroff, 2011)—but we use the term loosely. Case studies varied from small, single interventions (n = 2) (e.g., a Body Reprogramming course) to suites of services delivered by a Multi-Disciplinary Team (MDT) (n = 10). Multi-disciplinary services had typically been developed alongside or out of established hospital-based (e.g., rheumatology or pain management services. Most sites were National Health Service (NHS) funded and delivered (n = 10). However, we also included a private hospital that provided specialist fibromyalgia care to self-funded patients (n = 1), and a privately-developed programme that was providing services to NHS patients (n = 1). All case study sites were directly or indirectly influenced by emerging neurobiological concepts of Central Sensitisation (Cagnie et al., 2014; Gatchel and Neblett, 2018) (and the related term describing its clinical presentation, Central Sensitivity Syndrome (CSS)) (Boomershine, 2015; Mezhov et al., 2021). Service leads were keen to highlight innovation and participate in developing service recommendations.

TF and CC conducted 59 practitioner interviews, with: physiotherapists (n = 21); psychologists (n = 10); specialist medical doctors (n = 8); generalist medical doctors (n = 3); nurses (n = 2); pharmacists (n = 3); occupational therapists (n = 2); physical trainers (n = 2); health coaches (n = 2); administrators (n = 4); and Qigong teachers (n = 2). TF and CC also undertook ~200 h observation between January 2022 and February 2023. Most interviews were online, and some observations were of online self-management courses. (Many had switched to online delivery as a result of the Covid-19 pandemic.) Fieldnotes and interview data were transcribed, and NVivo used to manage the dataset. These data were used to support the development of core principles of care for fibromyalgia (see Author et al. forthcoming).

This paper is based on a focused analysis, employing Smith's (1987, 1990, 2005, 2006) Sociology for People (a social ontology also known as "institutional ethnography" [IE]) to explore the social organisation of practitioners' healing work. Smith's Sociology for People has previously been reported as a productive approach to analysing health systems (Campbell and Rankin, 2016; Cupit et al., 2020; Cupit, 2022). Smith's analytic focus on *work* in particular enabled us to centre our analysis on practitioners' situated knowledge of supporting people with fibromyalgia. As part of the analytic process, our attention was particularly drawn to disjunctures relating to ideas and practices around *chronicity*. Disjunctures have been described by Smith (2005, p.187) as tensions between "artificial realities of institutions and the actualities that people live"; they are the direct products of institutional systems organising people's knowledge and practice across time and place. As the analysis progressed, we sought to understand why fibromyalgia was so consistently presented as a chronic condition (across clinical specialities and patient groups), and in ways that seemed to inhibit the healing work of both practitioners and patients. We followed threads from our data to gain an understanding of the institutional systems involved.

Our study included a variety of practitioners from different specialities, professional backgrounds, and types of service. We observed that chronicity rhetoric consistently entered into healing work, and was activated (to different degrees and in various ways) by patients and practitioners. Some practitioners assumed "chronicity" as reflecting the nature of fibromyalgia and their patients' experiences. Others (often service leads/innovators) were proactive in challenging chronicity rhetoric. It was clear that, whatever practitioners' readiness to identify and discuss the problem, chronicity rhetoric was generating tensions in interactions between practitioners and patients. We resisted a tendency in qualitative research to thematically categorise practitioners or patients, as we were not *primarily* interested in the different "types"/perceptions of people, perspectives, or experience. Instead, we wanted to explore how the variously-expressed tensions relating to chronicity were socially organised. Using Smith's lens, we undertook this exploration by focusing on practitioners' work, examining tensions between different kinds of knowledge, and following traces of textual/institutional coordination (Cupit et al., 2021).

Our study is primarily focused on practitioners' knowledge and practice. However, we were able to observe patient care, and we were guided by patient experiences captured in the larger PACFiND study (Doebl et al., 2020, 2022; Wilson et al., 2022; Health Experience Insights [HEXI], University of Oxford, 2024) and other social science literature (Cupit et al., 2025). We were also able to draw on patient and carer discussions on Facebook groups (with consent) and the public and patient representatives attached to the PACFIND study. Most of the practitioners we observed and interviewed had long-term experience of the difficulties faced by people with fibromyalgia, and were committed to working with them to achieve tangible improvement. In keeping with Smith's approach, we focused on what happens (as reported or observed) rather than on practitioners' opinions. We aimed to better understand why problems occur, through mapping dominant institutional systems that coordinate frontline practice. This paper begins the mapping process, highlighting two institutional domains that we identified, namely "Biomedical Research" and the "Welfare Benefits" system. These are capitalised to highlight them as distinct "spheres of activity" (Smith, 2014, p.225), whilst also recognising extensive interconnectivity—the clues of which are present, but beyond the scope of this paper to explore.

3. Findings

In the first section, we make visible the healing work that is undertaken by practitioners and patients with fibromyalgia. Through an analysis of healing work, we identify a dominant and persistent *chronicity rhetoric* which instrumentally generates problems for practitioners and patients. In the second section, we show how chronicity rhetoric is activated and reinforced within two apparently separate institutional domains: (1) the Biomedical Research infrastructure that shapes services; and (2) the Welfare Benefits system, which shapes how patients know and act in relation to managing their illness.

3.1. Making healing work visible

3.1.1. Soothing the nervous system

New service models for people with fibromyalgia recognise that people are complex and integrated *body-minds* (Berrios, 2018) that are responsive to, and interactive with, their social/material environments. In other words, "everyone's disease is the product of the individual history of exposures [including a wide range of psychosocial stressors], superimposed on their underlying genetic susceptibilities" (Vineis et al., 2020). Psychosocial pressures get "under the skin" (Scambler, 2005) and need addressing to mitigate symptoms. Neurobiological concepts of Central Sensitisation and Central Sensitivity Syndrome (CSS) (Gatchel and Neblett, 2018) are important to such models, providing mechanistic explanations of fibromyalgia, and opportunities for treatments that involve desensitising (or "dampening down") a person's nervous system.

The following fieldnote reports one practitioner's explanation of fibromyalgia:

> *People with CSS are always primed for response to the next challenge. Group lead explains using computer/phone illustration: can have hardware or software problem. Broken leg is hardware problem; medicine is really good at fixing hardware problems. But CSS/fibromyalgia is a software problem, an information processing problem. All the body systems are off-kilter—on high alert. So how do you fix a software problem? Re-booting; that is what this course is all about. (Fieldnotes, Body Reprogramming Course)*

Such explanations of body-mind connectivity ran through individual and group consultations:

> *I talk about your brain and your nervous system and the peripheral nervous system, and I'm quite explicit in making links between mind and body and giving different examples to get that across. (W10)*

Practitioners observe that there is a "type" of person who suffers from fibromyalgia, and highlight that these patients have to work hard to emotionally regulate "threat". Work on emotional regulation involves learning to better manage the social situations which cause or contribute to symptoms. Practitioners emphasise that people with fibromyalgia often "push" themselves and need to learn to manage that instinct:

> *People with fibro, they'll push themselves to the Nth degree, so [you have to] rein them in […] they work very hard and that's what's got them in this mess in the first place. (W11)*

Recognising difficult circumstances (e.g., previous Adverse Childhood Experiences (ACEs), responsibility for children/elderly family with disabilities) was an important part of care:

> *[Describing a programme] We move into the personality types of people that get fibromyalgia, so we talk about the perfectionist and altruistic person, and every single one of them puts their hand up to either one or both, and they suddenly feel like they're being safely held. (E01)*

This validation is particularly important as, people with fibromyalgia are frequently represented as incapable or malingerers (Doebl et al., 2022; Wilson et al., 2022), and struggle to access services:

> *The complexity of the individual in front of you is increasing, and I think that is a reflection on the shifting shape of the NHS and social care in the fact that there are pressures on access to mental health services, access to social care, the benefits system has morphed and changed, and access to GP appointments is challenging (E03)*

The concept of "pushing" was seen by practitioners as both an individual character trait and a consequence of societal pressures, which in turn activate people's coping mechanisms:

> *[Referencing an educational psychologist / author] "Our culture says being hard on yourself is the correct way to be. Society is pushing us to keep pushing." Group lead encourages the group to consider "What do you use to feel better?" People spontaneously contribute "food, alcohol, TV for escapism" (others nodding). She suggests "online shopping (others laugh), smoking, drugs"? May work in the moment but payback later either physically, mentally and/or financially. Self-compassion generates that feeling but without the negative consequences. (Fieldnotes, Body Reprogramming Course)*

A healing approach that addresses underlying problems and supports gradual health improvements (Davis and Gonzalez, 2016) was seen as preferable to using medications or standardised biomedical interventions:

> *The sooner you can start soothing whatever part of that system it is the better, the less likely it is to become fixed in that person's nervous system. (E01)*

Using ideas such as "self-compassion", practitioners encourage patients to adapt their lives, manage stressors, and reduce symptoms of "hypervigilant stress system dysregulation" (Tidmarsh et al., 2022). This may involve so-called "lifestyle medicine" and/or more intensive therapies (e.g., trauma/relationship work). Many practitioners emphasise the importance of coaching that includes, for example, discussion of challenging relationships, care responsibilities, past experiences, purpose, priorities, etc. Clinician and patient work together in a therapeutic and consistent way that can be emotionally demanding for both parties:

> *Fibro patients sort of tend to have, tend to present with higher [anxiety and depression] scores than other chronic pain patients, so it can mean that you're quite exhausted at the end of a clinic. You're hearing a lot of very difficult traumas. You might be the first person they've shared that with […] it's [often] a similar trauma after trauma story. (E04)*

There was a recognition that fibromyalgia is different to many of the problems presented to health services—e.g., a "broken wrist" with a clear path to healing. Healing work was understood as a delicate process, particularly as patients have limited control over socioeconomic and contextual challenges which contribute to their symptoms:

> *Sometimes, people get better but … you can be much, much better […] that doesn't mean their pain has gone away, but they are managing, and they know what to do (S01)*

Thus, healing work was often described as "damage limitation", especially when patients have experienced years of unmet need, iatrogenic treatment, and/or socioeconomic constraints:

> *I get some people, 10 or 15 years down the line. I feel all I can do at that point is almost damage limitation. It sounds really horrible doesn't it but, at that point, I'm then going, "Gosh, actually now you've got more symptoms because of all this polypharmacy you're on, because of all these other [problems]." If I can try and stop that, [I will]. [But] often, by that point, their symptoms have become so overwhelming in every single part of their body that they actually can't make as big a leap forward as you can when you get in early. (E01)*

3.1.2. Disruptions related to chronicity rhetoric

Chronicity rhetoric caught our analytic attention, as representations of fibromyalgia that caused problems for practitioners and people with the condition. Many practitioners spoke of the need for patients to "manage" symptoms (as above) and prevent flare ups. Their understandings reflect both a dominant "self-management" discourse (Kendall and Rogers, 2007), and their frontline experience. Nevertheless, some still challenged the notion that people with fibromyalgia should necessarily resign themselves to being chronically disabled, and attributed people's experiences of chronicity to failings in health and social support (as above). Tensions between chronicity rhetoric and their current opportunities to support recovery/improvement were evident even in the accounts and observations of those who had witnessed chronic suffering. Practitioners highlighted problems with giving patients an expectation that fibromyalgia may only be "manageable":

> *[People] are told that this is the condition, nothing can heal, they have to live with [fibromyalgia] to the end of their lives. Only thing they can do is a bit of stretching or a bit of qigong. […] At the moment, NHS [says] "Yeah, you have this condition for the rest of your life". This is awful. (S02)*

Although fibromyalgia is categorised as a "chronic pain syndrome" (Arnold et al., 2016), practitioners drew on their practical, situated knowledge that improvement and/or full recovery may be possible—even after many years of illness. They saw this as a valid source of hope:

> *When you see these patients get better having [previously] been given no choice, no option, being told that this is what it's always going to be, it's really rewarding. […] I love getting these people better (W15)*

Practitioners' experience is supported by qualitative studies, and many anecdotal accounts, of people who have recovered (Mengshoel and Heggen, 2004; Eik et al., 2022; Juhlin et al., 2024; Baumgarten, 2015; Neuffer, 2024)—some of whom have become activists in this arena, seeking to offer hope to people with fibromyalgia and other similar syndromes (Alme et al., 2023). In the following sections, we draw attention to two institutional domains, in which chronicity is propagated as a primary and overruling way of knowing what fibromyalgia is (and what can be done about it). First, we highlight Biomedical Research, which governs the planning, funding, and delivery of services. We show that, within this domain, conditions such as fibromyalgia (which lacks evidence of effective treatments from high-quality clinical trials) are categorised as chronic, and face obstacles to investment. Second, we highlight the Welfare Benefits system within which patients are forced to emphasise their disability in order to access financial support.

3.2. Socially organised chronicity rhetoric

3.2.1. Chronicity in Biomedical Research

Influenced by the tenets of Evidence Based Medicine (EBM), and positivist science, the Biomedical Research infrastructure has incorporated ideas of clinical efficacy and cost-effectiveness such that reductive, and often singular treatments are valorised and prioritised. Biopsychosocial services thus represent a paradigm shift:

> *I had a colleague [who argued that], "We're dealing with [a patient's] health issues, all the other stuff somebody else can sort out". But it's recognising that interconnectedness. You can't have one without the other, that's the biopsychosocial model isn't it? We need a new paradigm, or a shift certainly. (E22)*

A major obstacle faced by practitioners working in biopsychosocial services is that they lack established, "evidence-based" ways of demonstrating that they *work* (as established through gold standard clinical trials). Below, we illustrate how the hegemonic position of EBM within Biomedical Research helps to construct fibromyalgia as a *chronic condition* with detrimental consequences for new service development.

Our illustrative example centres on a complaint, brought by two parties including the ME Association, to the UK's Advertising Standards Agency (ASA) about a "supported recovery programme" (Ruling on The Chrysalis Effect Ruling on The Chrysalis Effect Ltd, 2023). Both the ME Association and The Chrysalis Effect (a not-for-profit organisation and a PACFiND study site (de-anonymised with permission) support people with Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS) and fibromyalgia, due to their overlapping symptoms. The ME Association's complaint centred on The Chrysalis Effect's use of the term "recovery" in relation to their programme.

The ASA complaint was upheld in September 2023, with the ASA determining that the service "should hold scientific evidence in support of the claims that their programme could aid the recovery" (preferably "trials conducted on people") (ibid.). This followed an earlier, unsuccessful complaint brought by the ME Association. At the time of data collection for this study, an NHS pilot version of the "recovery programme" was underway, and poised for expansion. However, the ASA ruling led NHS commissioners to demand substantial changes to the programme (e.g., removing references to "recovery") that its developers considered too undermining of the programme (as well as costly and onerous to implement). At the time of writing, the developers have withdrawn the programme for NHS patients.

The ASA's determination (that there was not enough trial evidence to support claims about recovery) is hooked into a dominant biomedical infrastructure, in which clinical trial evidence is the gold standard. Within these governing systems, biopsychosocial (and often locally-developed) services find it difficult to demonstrate benefit (i.e., that healing work *works*). As one service developer commented, clinical trials are often not the best tool to demonstrate the usefulness of complex interventions, and therefore there is little such gold standard literature available to justify their programme:

> *Any evidence that we send in [responses to the ASA] is not accepted because the evidence that they measure it against is the existing literature. [But] the existing literature, everything that has been published on research for chronic fatigue and ME and fibromyalgia, is based on the biomedical acute disease model. [Service developer, Chrysalis Effect]*

Biomedical Research and its hierarchy of evidence determines the particular forms of knowledge that are cemented as authoritative. EBM is crucial to evaluating the benefits and harms of medicines, demonstrating which interventions *work* and which do not. But EBM has more limited applicability to a complex and multifaceted trauma-informed package of biopsychosocial support like the Chrysalis Effect's programme. Whilst core elements (e.g., health coaching, education, peer support) are supported by scientific and experimental evidence, the Chrysalis Effect programme is not a singular or standardised intervention. And subjective symptom impact questionnaires (SIQs) and patient testimonials (that are enrolled by programme developers as more pragmatically useful forms of evidence) have little authority within the Biomedical Research domain.

The kind of healing work highlighted in this paper is particularly reliant on the complex and difficult social and psychological work that is required from patients. Unlike interventions that involve medication or a prescribed behavioural regime, patients have to figure out what (in their individual lives) may be important to address various socioeconomic stresses. The nature of these stresses is of course extremely diverse, and patients may conclude, for example, that they should end an abusive relationship or seek guidance on a housing problem. The benefits of supporting this kind of work through individualised and therapeutic coaching is difficult to prove. Clinical trials cannot account for, or control for, such diverse social challenges or the individual neurobiology that may be involved in addressing them. In practice, trials of biopsychosocial models of care may not demonstrate improved outcomes, *not because the interventions (care practices) involved are unfounded (non-evidence-based)*, but because patients do not have the social or psychological resources to maximise benefit from them. In both the example highlighted, and in circulating discourse about “evidence”, a disproportionate and linear focus on interventional procedure and “outcomes” obscures the work of patients, generating widespread conflation of clinical trial evidence with the value that can be obtained from biopsychosocial care.

Although the Chrysalis Effect example is highly specific, similar problems were arising for the other emerging biopsychosocial services we studied. These used approaches that, while based on various forms of evidence (including some trial evidence for particular interventional elements), did not rest *exclusively* on EBM’s standardised tools (Langweiler, 2021; Schrecker, 2023). Many reported an ongoing struggle to justify the development and maintenance of services and were increasingly undertaking pre-screening to determine whether an individual patient would be able to “engage” with the service (and therefore achieve positive evaluation outcomes).

EBM is an “active discourse” (Mykhalovskiy, 2001) in which “evidence” and “effectiveness” are instrumentally linked to understandings of chronicity. As we have highlighted with the ASA example, it is extremely difficult for new fibromyalgia services to demonstrate that they are “effective” using EBM’s evidential tools. If it can be argued that nothing works to treat fibromyalgia, then it is only a small step to creating textual representations of fibromyalgia as “chronic”—and practitioners to be very wary of using “recovery” language which is seen as contrary to the established evidence.

Chronicity rhetoric arising from the Biomedical Research infrastructure is adopted in other situations too. For example, informants in this study noted that patient organisations have good reason to focus on the chronicity of conditions such as fibromyalgia:

> *The ME Association [have a newsletter and] they put obituaries in there. It’s all about the suffering. They are absolutely focussed that they want more and more funding to do more and more research. The drug trials that they support are all reported on there—cancer drugs to be used on people, anti-psychotics, all really quite strong medicines that seem to be the route that they are focussed on. (E17)*

In order to secure donations, patient charities and affiliated researchers emphasise that conditions such as fibromyalgia have no cure (see Pathirana et al., 2017). Donations fund (almost exclusively) pharmaceutical research so that “one day we hope we might discover a diagnostic marker and effective treatments” (The ME Association, 2024). It therefore makes sense for such organisations to assert that “getting better” or “recovering” from fibromyalgia is rare, and that chronicity is the more probable trajectory (Shepherd, 2021):

> *Q: WHAT ARE MY CHANCES OF RECOVERING?*
>
> *A: Prognosis is variable and not easy to predict. In some cases, the symptoms gradually disappear over months or years. However, as with ME/CFS, [fibromyalgia] often turns into a chronic illness which varies in severity over a long period of time.*

The production of new evidence (based on new biopsychosocial services) is difficult for many reasons including methodological hegemony (i.e., the dominance of clinical trials) and lack of research/funding resources to undertake robust research on such complex programmes. These difficulties are exacerbated as a result of patients’ reluctance to allow improved health outcomes to be formally documented—a problem which is linked to concerns about the removal of welfare benefits (see next section):

> *[People’s reluctance to document improvement] definitely needs to be more widely acknowledged as a big, big factor in demonstrating [service] outcomes. You will be speaking to somebody, who clearly felt safe and comfortable to express how buzzing they were about the change in their life, but their [Patient Recorded Outcome Measures] still look rubbish. […] They don’t trust the system, do they? (W21)*

Through multiple and intertwined mechanisms, the institutional infrastructure of Biomedical Research consistently reinforces fibromyalgia’s chronicity, influencing the circulating discourse about what is possible and the services in which it is worth investing.

3.2.2. *Chronicity in the Welfare Benefits system*

The Welfare Benefits system is a second dominant infrastructure which regulates people’s knowledge and practice, affecting healing work. In 2023, fibromyalgia was the “fourth most common condition to get an award of PIP [the UK’s main disability payment] out of over 500 conditions listed by the Department for Work and Pensions” (Benefits and Work, 2024). In this section, we highlight how the Welfare Benefits system shapes the everyday experiences of people with fibromyalgia, encouraging the production and dissemination of chronicity rhetoric. Our analysis is from practitioner accounts, but these correspond with the accounts of people with fibromyalgia online and across other forums, and in literature relating to patient experiences (Cupit et al., 2025).

Informants working in biopsychosocial services highlighted that patients are often reluctant to document improvements in their health due to concern that this could jeopardise their access to financial or other disability-related social support:

> *Maybe they go, “This is a form, I’ve got to be careful what I write here, this is the thing that’ll get looked at [as part of a benefits assessment].” (E22)*

The Welfare Benefits system is “at odds” with healing work because it demands that people “prove how bad things are”:

> *The system by which people are living, which is usually the benefit system, it’s about proving your disability and proving how bad things are. So, it’s at complete odds with what we are trying to do as a service to improve somebody’s quality of life, improve people’s wellbeing. They are scared of saying that they feel better because you know it could mean financial implications that they can’t cope without. (W21)*

In order to claim disability benefits (e.g., Personal Independence Payment [PIP]; mobility vehicle/transport; accessible/free parking [“blue badge”]; employment rights; and wider benefits related to housing and social care (Disability Claims, 2020; Benefits and Work, 2024) (GOV.UK, 2024a)), patients have to demonstrate their “impairment”. On top of coping with everyday symptoms and difficult socioeconomic situations, patients must engage with benefits assessments that are laborious and stressful:

> *I’m well aware of the very difficult social situations that many of the patients are in, and I’m constantly reminded of that when I’m being asked to write letters of support for change in accommodation, for work support, financial issues etc. (E23)*

Support with benefits applications has become central to online/community forums, as little help is available through health services:

> *GPs don't always help with PIP applications, in fact quite rarely now I think because they're pushed for time. It's quite a lengthy document, [so patients] struggle to complete the forms and the rejection rate is quite high in terms of PIP awards. So we get asked, but that's quite an onerous task on top of delivering therapy as well. A benefits advisor would be helpful if I had attached to the service. (W18)*

People with fibromyalgia often end up in the welfare system after struggling to address problems in the workplace and/or cope in jobs that are difficult, low paid, and inflexible (Henderson, 2020). Their battles straddle employment and Welfare Benefits systems:

> *I find most patients are either worried about getting back to work because they're feeling that their job's pressing them to go back and they don't feel ready, or alternatively they want to go back and their job is […] trying to finish them (W07)*

> *Our expert patient, who's just absolutely wonderful, [led a group session recently] about leaving work and going on to benefits—which was what she did, and it really helped her because she couldn't work. Then it spiralled into a conversation about, "Oh, I want to leave work and go on benefits, how do I go about it, what do I do?" And I'm like, "Ooh, okay!" Then one girl got really upset because she was like, "Oh my god, is this my future? I've got to give up my job?" (E01)*

Applying for benefits and contesting decisions requires considerable emotional, intellectual and practical effort, which can itself threaten healing:

> *This session felt tricky for the facilitators. […] At least three have been dealing with stressful issues like benefits or bereavement which undermines their ability to work with the course content. One informant asked a question "What's the point of all this? I'm never going to get better". (Fieldnotes, Body Reprogramming Course)*

Fear of financial repercussions may, alongside many other stresses, inhibit the healing process:

> *So, people that are on benefits. […] are fearful because if they do get better, they could lose their benefits. (W18)*

Health professionals may be called upon to provide evidence (GOV.UK, 2023) for benefit assessments. Patient forums consistently report that people with fibromyalgia need to emphasise the chronicity and severity of symptoms, that a rheumatology consultant's letter may be required, and that the prescription of multiple medications may support their case (see also Lempp et al., 2009; Diver et al., 2013; Madden and Sim, 2016). This in turn helps to organise patients' perceptions of what will work best for them around a "(bio)medical model":

> *Patients still want the medical model, don't they? It's quite hard to change mindset, they'll still want that "go to a doctor, get fixed" type thing. (E23)*

Many patients turn to online forums, but these can also act to reinforce fear and hopelessness, and to undermine healing work:

> *If you are living by what you find on a fibromyalgia forum, I think from what patients have told us, that can be just really negative and it just becomes a dumping ground for everybody's angst with the [Department for Work & Pensions (DWP)], or the government, or their husband, or their wife, or their GP, or their physio, or their neighbour or … (S03)*

While financial security from benefits was recognised as essential, informants were concerned about the codification of people with fibromyalgia as chronically disabled. During the data collection phase of this study, disability activists were celebrating the success of their campaign for formal recognition of fibromyalgia as a disability (Equality Act, 2010) following UK Parliamentary debate (Barber et al., 2019). Consequently, the diagnosis of fibromyalgia became a qualifying condition for Personal Independence Payment (PIP) (GOV.UK, 2024b), the primary welfare benefit for working-age people with disabilities. This meant that fibromyalgia diagnosis was increasingly being recognised as a gateway to a range of other benefits (although reports on online forums suggest considerable heterogeneity of experience across regions/assessments). Paradoxically, in some ways this recognition was making practitioners' and patients' healing work more difficult as "chronicity" was a barrier to engagement:

> *Fibromyalgia is being designated the label of a formally recognised disability, so there's celebration in the camp now because it means that if they get that diagnosis, then they've got guaranteed benefits. That's what we're up against all the time. […] So, somebody gets a diagnosis, and now they'll be able to get a blue badge [entitlement to use accessible parking spaces, free of charge]. They've had to fight to prove their illness [and] they're terrified of getting well because then they'll lose their benefits, that they absolutely need right now because they're poorly. (E22)*

As we have shown, the Welfare Benefits system organises patients to consciously or unconsciously embrace rhetoric relating to fibromyalgia's chronicity. Our analysis highlights how an inflexible welfare infrastructure forces people to mobilise chronicity rhetoric to obtain socioeconomic stability: patients constantly work to prove their illness at the expense of focusing on the labour-intensive work of healing.

4. Discussion

Fibromyalgia is routinely represented across policy and practice as a "chronic" or "long term" condition. Drawing on Smith's Sociology for People, we have shown that chronicity (a ruling way of knowing about fibromyalgia and its prognosis) is produced and reinforced through the institutional infrastructures for Biomedical Research and Welfare Benefits. While these spheres of knowledge production are in many ways distinct, there are also interconnectivities, which have been beyond the scope of this paper to explore. The International Classification of Diseases (ICD) legitimises medical conditions and underpins both pharmaceutical research and eligibility criteria for welfare benefits, for example (Galvez-Sánchez and Reyes del Paso, 2020).

Institutionally produced and reinforced chronicity rhetoric is instrumental in shaping (and often impeding) the development of new holistic (biopsychosocial) services, and discouraging patients from investing time and energy into making changes in everyday life that are needed for recovery. Whilst chronicity *does* accurately reflect the findings of published epidemiological research and the experience of many people with the condition, it is also *challenged* by practitioners and patients attempting to harness (new) understandings of neurobiology, with emancipatory goals of improvement and/or recovery (see Kjeldsen et al., 2024). Practitioners and patients argue from practical experience that improvement and/or recovery *are possible* with the right support and individual resources to make changes.

Our findings align with Bister's (2018) analysis of the concept of chronicity, and her conclusion that "the classification of chronicity acts as a tool of description (of people or their conditions), regulation (of therapy, health care or administration), and connection to infrastructures of care (practised technologies or standards of various kinds)". From our study, we highlight that people with fibromyalgia risk becoming stuck in a situation which impedes recovery, abandons them to lifelong reliance on iatrogenic medications, and disincentivises them to work (see Dwyer et al., 2020; Hoynes et al., 2023). Chronic pain and fatigue may become a fait accompli in practice, with detrimental implications for both patients and public funding. The implications are both material (in people's bodies and lives) and discursive (in public attitudes towards, for example, a "benefits culture" (Tyler, 2015)). A better balance in health and welfare discourse is needed between a recognition of long term complex illness, and the provision of hope, tangible support and the necessary institutional infrastructure for practitioners, patients, and benefits advisors to cooperate towards mutually beneficial health improvement goals.

As Zajacova et al. (2021) have previously highlighted, pain is a "sensitive barometer of population health and well-being". Both health and welfare services should recognise the changing face of illness in contemporary society, and restructure systems and processes to accommodate widespread conditions such as fibromyalgia. For example, health service managers could rethink their use of evidence in the development of services for fibromyalgia and other similar syndromes. Welfare Benefits systems could better support people's need for flexibility whilst working on recovery. Planned welfare reforms (GOV.UK, 2024c) will allow people to "try work without fear of losing their benefits", but it will be important for this aspiration to be reflected in less oppressive welfare benefits assessment processes, and healthcare systems that simultaneously support healing and the work that healing requires.

Smith's Sociology for People (our analytic lens) has enabled us to study how contemporary forms of managerial accountability are practically shaping the frontline work of practitioners and patients (Griffith and Smith, 2014). Chronicity rhetoric does not bubble up from nowhere in multiple people's interactions, across multiple domains of practice—and problems are therefore not addressed by instructing individuals to use language differently. Instead, chronicity rhetoric is a *socially-organised* way of knowing and talking—a product of various *system-level* forces. In a contemporary society that is increasingly coordinated through a surfeit of electronic and textual technologies (including "artificial intelligence") that operate "behind our backs" (opaque to service users and providers) (ibid., p.18), it is crucial to interrogate *how systems work*, as well as *how people experience* illness and healthcare. This kind of research is often highly challenging to undertake as it involves going back and forth between local and management settings. Our study has added to a growing repertoire of health services research that shows the usefulness of Smith's Sociology for People (otherwise known as "Institutional Ethnography") for practically undertaking this systems-focused work.

5. Strengths and limitations

This paper uniquely highlights the healing work of practitioners working in biopsychosocial services for people with fibromyalgia, and the challenges resulting from chronicity rhetoric that is propagated within the institutional infrastructures of Biomedical Research and Welfare Benefits. It reports practitioners' accounts of events and practices, and issues faced by patients. We have carefully triangulated practitioner accounts with those of patients (PPIE representatives, this study's other workstreams, online forums, literature analysis). However, the patient experiences reported here are mediated through the voices of practitioners, and specifically through practitioners whose preferences are orientated towards a biopsychosocial framework. Further work is needed to interrogate the institutional infrastructure that is involved in producing and reinforcing chronicity and inhibiting the recovery of people with fibromyalgia.

6. Conclusion

Chronicity rhetoric embedded in Biomedical Research and Welfare Benefits infrastructures has a negative impact on healing work. Using Smith's Sociology for People, we have begun to show how chronicity rhetoric is adopted by a variety of stakeholders including researchers, practitioners and patients—with potentially harmful consequences. We have shown that people with fibromyalgia may be better able to achieve tangible health improvement and (re)integration into everyday life if problematic features of the institutional infrastructure are tackled. Further work is needed to address (1) the processes by which evidence is employed in the development of holistic (biopsychosocial) services, and (2) how welfare systems can accommodate people with complex, fluctuating, and stress-sensitive conditions. The findings presented in this study are applicable to the management of fibromyalgia and similarly difficult-to-treat conditions (e.g., rheumatological conditions, ME, CFS). These conditions are having increasingly problematic impacts on health, wellbeing and economic productivity worldwide.

CRediT authorship contribution statement

Caroline Cupit: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Teresa Finlay:** Writing – review & editing, Investigation, Formal analysis. **Catherine Pope:** Writing – review & editing, Supervision, Resources, Project administration, Funding acquisition.

Ethics statement

Ethical approval was granted by an NHS Research Ethics Committee (REC reference 20/NI/0157; IRAS ID: 275725) in November 2020.

Conflicts of interest

The authors declare no conflicts of interest.

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Data availability

The authors do not have permission to share data.

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