Suffering in Cyberspace: Biopolitics, Habitus and ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)

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Abstract

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This thesis investigates how people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) use digital environments to communicate suffering, build community, and challenge the institutional disbelief that surrounds their illness. Drawing on digital ethnography, illness journals, and qualitative interviews, it explores how online interaction becomes a site of knowledge production, care, and political action.

The study introduces the concept of *suffering-capital* to describe how the emotional and communicative labour of illness generates value and legitimacy within moral and bureaucratic economies. It develops the idea of a *political–biosocial habitus*, drawing on and reworking Bourdieusian conceptions of *habitus* and capital, showing how digital illness publics consciously cultivate shared dispositions and forms of expertise that reconfigure the field of health knowledge. Together, these frameworks illuminate how power, visibility, and care are negotiated through digital practice.

Empirically, the research traces how people with ME/CFS transform isolation into collective infrastructure through platforms such as MEpedia, online benefits forums, and campaigns like *Millions Missing*. Within these spaces, participants collaboratively curate and test treatment protocols, translating biomedical research into practical guidance and shared care strategies. The analysis reveals how welfare bureaucracy converts impairment into administrative labour, and how patients counter this through acts of solidarity, creativity, and mutual expertise.

The thesis extends disability theory by integrating embodied fluctuation and relational ethics into the social model, culminating in a *frailty-informed relational model of care*. This model reframes frailty as an inclusive, co-produced framework for chronic illness policy and practice. Overall, the study contributes to disability studies, digital sociology, and medical humanities by demonstrating how suffering, when collectively mediated, becomes a source of resistance, knowledge, and social transformation.

Declaration

I declare that no portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification at this or any other university or other institute of learning.

Glossary of key terms

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Biopolitics
A concept most closely associated with Foucault, referring to the ways modern power operates through the management, regulation, and optimisation of life itself. Biopolitics concerns how bodies and populations are governed through medical knowledge, public health regimes, welfare systems, and normative assumptions about productivity, risk, and normality. In this thesis, biopolitics frames how people with ME/CFS are positioned within systems that seek to measure, classify, legitimise, or discipline illness, including through clinical guidelines, research priorities, and digital infrastructures.

Biosocial Habitus
An adaptation of Bourdieu's concept of habitus that emphasises how embodied dispositions are co-produced through biological experience and social mediation. Within this thesis, it refers to the shared orientations of people with ME/CFS as they navigate digital, medical, and political fields simultaneously.

CBT (Cognitive Behavioural Therapy)
A structured psychological therapy focused on identifying and modifying patterns of thought and behaviour. In ME/CFS contexts, CBT has been used in some clinical approaches with the aim of supporting coping and symptom management. Its application has been contested when framed as addressing purported psychological causes of the illness rather than as optional support for living with chronic symptoms.

Cyberspace
A term used in this thesis as a broad descriptor for networked digital environments and their social, cultural, and technical infrastructures. It encompasses the expanding terrain of online life, including Web 2.0 platforms such as social media and forums, emerging Web 3.0 imaginaries and infrastructures, and AI-mediated systems that increasingly shape communication, visibility, and participation. Cyberspace is treated here as a field in which power, knowledge, and belonging are negotiated through platform architectures, economic logics, and cultural norms.

Digital Habitus
A set of embodied and cognitive dispositions that emerge through repeated interaction within digital environments. Extending Bourdieu's framework, digital habitus describes how individuals and communities learn to communicate, perform, and interpret suffering through the affordances and constraints of online platforms.

Digital Health Communities
Online spaces, such as forums, Facebook groups, or patient-led databases, where people with chronic illnesses share information, experiences, and advocacy. Within this study, they are understood as digital fields in which knowledge, solidarity, and collective habitus are formed.

Doxa
Following Bourdieu, doxa refers to taken-for-granted beliefs that appear natural within a social field. In digital contexts, doxa manifests through algorithmically reinforced norms that shape what is perceived as credible or legitimate knowledge about illness and suffering.

Epistemic Injustice
A concept associated with Fricker describing harms that occur when someone is wronged in their capacity as a knower. In this thesis, epistemic injustice names the ways people with ME/CFS may be disbelieved, dismissed, or deprived of interpretive resources, including through medical encounters, media framings, and digital cultures that shape who is heard and whose knowledge is recognised.

Field
A structured social space with its own rules, hierarchies, and forms of capital. This thesis treats cyberspace as a field in which communicative practices around disability and illness are negotiated through power relations shaped by technology, culture, and economy.

GET (Graded Exercise Therapy)
A rehabilitative approach that involves increasing physical activity in planned, incremental steps. GET became prominent in some clinical guidance for ME/CFS, often based on assumptions about deconditioning. It is controversial, particularly because many people with ME/CFS report that exertion can worsen symptoms, and because the approach has been criticised for insufficiently accounting for post-exertional malaise.

Habitus
The system of durable dispositions that guide perception, thought, and action (Bourdieu). Habitus bridges structure and agency: it is shaped by social conditions yet reproduces them through practice. In this thesis, habitus functions as both a conceptual framework and a methodological tool for interpreting patterns of digital behaviour.

Long COVID
A post-viral syndrome following COVID-19 infection that shares overlapping symptoms with ME/CFS. Its recognition has influenced medical and public understandings of post-viral fatigue conditions.

ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome)
A chronic, multi-system illness characterised by severe, persistent fatigue, post-exertional malaise, cognitive dysfunction, sleep disturbance, and autonomic, neurological, and immune abnormalities. Symptoms fluctuate in severity and can lead to profound functional impairment.

PACE Trial
A major UK-based clinical trial that evaluated cognitive behavioural therapy, graded exercise therapy, adaptive pacing therapy, and specialist medical care for ME/CFS. It has been widely criticised by patients, clinicians, and researchers for methodological and reporting issues, including outcome changes and debates over the interpretation of results. In this thesis, the PACE trial functions as a key reference point in conflicts over evidentiary authority, legitimacy, and the politics of expertise in ME/CFS.

Pacing
A self-management strategy used by people with ME/CFS to regulate activity and prevent post-exertional malaise. It involves balancing energy expenditure with rest and monitoring symptoms to avoid overexertion.

Patient-Led Research
Research initiated, designed, or conducted by patients and communities, often in response to gaps in institutional attention, funding, or credibility. In this thesis, patient-led research includes forms of collective inquiry, data gathering, and interpretive work developed within digital health communities, and is treated as a significant mode of knowledge production that can challenge dominant hierarchies of expertise.

Pharmakon / Metapharmacology
Derived from Stiegler, the pharmakon denotes something that is both remedy and poison, and is also scapegoated as a 'problem' in itself. Applied here to digital technologies, metapharmacology captures the dual nature of cyberspace as simultaneously curative and toxic, as a medium that fosters connection and empowerment while also reproducing fatigue, exploitation, and exclusion.

Platform Affordances
The action possibilities and constraints that digital platforms enable through their design, interfaces, and governance. In this thesis, platform affordances refer to how features such as character limits, reaction buttons, algorithms, moderation policies, privacy settings, and group structures shape how illness is narrated, how support is organised, and how knowledge circulates.

Political-Biosocial Habitus
A term developed in this thesis to describe the shared dispositions of people with ME/CFS as they engage in digital knowledge-making and advocacy, negotiating medical, social, and political fields simultaneously.

Post-Exertional Malaise (PEM)
A hallmark symptom of ME/CFS describing the worsening of symptoms following physical or cognitive exertion. PEM may be delayed by several hours or days and can last for prolonged periods, severely limiting activity.

Severe / Very Severe ME/CFS
Clinical classifications referring to individuals who are largely or completely housebound or bedbound, often with significant sensory sensitivities and reliance on carers for basic needs.

Shadow Knowledge Economy
A concept developed in this thesis to describe forms of knowledge produced within health communities that carry substantial value, including experiential expertise and, at times, sophisticated epistemic and methodological labour. This knowledge circulates through peer networks, online forums, and patient-led archives, but it is often marginalised, rendered invisible, or treated as illegitimate because it does not align neatly with dominant institutions and fields of power such as biomedicine, state governance, or mainstream media. The term highlights how communities generate, test, and preserve insight that can remain inaccessible to official cultures of evidence due to structural barriers in recognition, translation, and uptake.

Suffering-Capital
A theoretical extension of Bourdieu's concept of capital, developed in this thesis. It denotes the conversion of communicated suffering into social, symbolic, or cultural value within economies of visibility. The term highlights how narratives of pain and endurance circulate as moral and affective currencies in networked publics.

CHAPTER 1: INTRODUCTION

Introduction

Suffering does not become socially consequential simply because it is endured. It becomes public, and therefore contestable, when it is expressed, mediated, and recognised within infrastructures of communication. Recognition is uneven as some forms of pain are amplified and treated as credible, while others are doubted, psychologised, or ignored. In contemporary digital life, platforms, institutions, and algorithmically organised systems increasingly arbitrate empathy and credibility, shaping whose hardship circulates and whose disappears.

This thesis investigates how delegitimised suffering is made visible, believable, and politically meaningful through digital mediation. It focuses on people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a condition long marked by medical uncertainty, public scepticism, and gendered dismissals. ME/CFS is a form of suffering that has had to be argued for as much as endured. Precisely because its legitimacy is persistently contested, it offers a critical lens through which to examine how sufferers use digital environments to articulate illness, forge community, and negotiate recognition when traditional institutions fall short. I argue that suffering is not only embodied but socially constructed through mediated recognition, and that digital infrastructures shape how (and whether) contested illness becomes credible, shareable, and politically actionable.

This thesis has four aims. (i) To examine how people with ME/CFS use digital environments to communicate delegitimised suffering. (2) To analyse how these practices shape identity, community, and epistemic/biopolitical capital. (iii) To explain how such practices interact with, resist, or reproduce wider fields of power and regimes of suffering, and (iv) to contribute to theory on suffering, care, disability, and media power by developing the concept of suffering-capital.

The thesis advances a central claim, that suffering becomes socially “real” through mediated recognition. Experiences of pain and hardship acquire public weight only when they are expressed in forms that audiences, institutions, and platforms can interpret as

legitimate, making recognition a key site of power in the organisation of credibility and care.

To analyse these dynamics, I combine Bourdieu's concepts of field and *habitus* with biopolitical theories of governance. I also introduce the term *suffering-capital*: the socially convertible value that can accrue when hardship is rendered legible and credible within particular fields. ME/CFS provides a critical case through which to develop this framework because its legitimacy has been persistently contested, forcing sufferers to negotiate recognition across medicine, media, welfare, and platforms.

This chapter will therefore (i) expand on the problem of suffering, (ii) explore the conceptual background that underpins this thesis, before (iii) situating this framework within mediation, media power, and sociology. It will then (iv) provide a background to ME/CFS as the population focus of this study, before delivering (iv) the research problem, aims, and questions, (v) a brief methodological overview and (vi) an outline of the forthcoming thesis structure.

The Problem of Suffering

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Understandings of suffering have traditionally centred on the endurance of physical pain. However, it is now widely accepted that suffering encompasses a broad range of experiences beyond the physical, including material deprivation, social injustice, isolation, bereavement, loss, or deprivation of civil liberties (Cassell, 2004; Wilkinson, 2005; Renault, 2017). Accepting this expanded view, suffering can be defined as a state of extreme physical, mental, social, emotional, and financial hardship or distress. Crucially, suffering is uniquely experienced by those enduring it, making shared experiences paradoxical as no two individuals live or embody suffering in exactly the same way, linking it to isolation. Wilkinson (2005, p. 16) suggests the 'unsharability' of suffering may be one of its most essential attributes. Indeed, it may be precisely because suffering is confined to personal experience that it causes such profound distress and harm. In this sense, suffering is not necessarily something that diminishes over time, rather, once initiated, it holds the potential to manifest further harm and distress. This thesis argues that suffering is best understood as a communicative and political phenomenon as it becomes socially “real” through performances and infrastructures of mediation.

The distinctly individual experience of suffering makes exploring the social characteristics of the experience complex. However, it can be argued that to the same extent that pain and hardship are isolating, they are also distinctly social phenomena. What Cassell (2004) asks us to consider is that 'part of the pain experience arises from the fact that once there is pain from whatever source in a body part, that in itself sets in motion responses that change the pain experience and the reaction of the patient and others to the pain' (p. 269). These responses can manifest in diverse ways; for example, someone suffering from a headache could wince and wrinkle their eyes to communicate their discomfort, another person may verbally articulate their experience, while another person could disassociate or actively conceal their experience. In this way, the performance of pain between those living the experience and their audience is itself crucial to any experience of suffering. It is through this performative communication that suffering manifests, as, without it, endurance is private. As such, 'suffering exists, and often can only be understood, in the context of others' (Cassell, 2004, p. 34). Consequently, through a shared and communicated act, a private experience of endurance graduates to a public or collective understanding where the label ‘suffering’ can be applied. With this notion, it must be appreciated as a multifaceted phenomenon which manifests meaning and order through a combination of

lived, observed and performed experiences. Indeed, suffering is itself a distinct multiplex communication genre.

This interplay between suffering and communication resonates deeply in my own experience. As someone with autism, I struggled to express pain verbally during childhood, and my family would often comment on my seemingly ‘high pain threshold’. When I had epileptic seizures or resulting injuries, I was told that seizures affect witnesses more than those experiencing them, as while I was unconscious during seizures, others were not and found it distressing to witness them. Post-seizure, I lacked the linguistic means to articulate my ongoing distress about the experience, for example, the feeling of unwellness before and after the seizure. I accepted this narrative until I witnessed another person’s seizure, which revealed the myth as my experience of witnessing felt inconsequential to any of my previous experiences of having a seizure. This highlighted to me the importance of socially conventional expressions of suffering for shared understanding. People with autism face what Costello et al. (2021) describe as 'communication vulnerability' (p. 289), where distress expressions may be atypical and are therefore misinterpreted or minimised by society. However, communicative vulnerability extends beyond neurodivergence, particularly affecting many disabled individuals, people with learning disabilities, those with chronic illness, and children.

I use this personal anecdote to illustrate that if suffering must be expressed to be recognised, then recognition is a site of power. The “unsharability” of suffering may make it deeply isolating, but its translation into social life, for example, through gestures, words, or performances, exposes the inequalities in whose pain is validated and whose is ignored. To frame suffering as communicative is to acknowledge that it circulates unevenly, is mediated by norms of expression, and is filtered through social hierarchies. The politics of suffering, therefore, lies not only in its causes but in its recognisability. When recognition is a precondition for care, solidarity, and justice, communicability becomes a structured inequality rather than a neutral process. This chapter, therefore, treats recognition as an organised accomplishment shaped by norms of expression and infrastructures of mediation.

Conceptual Background: Suffering as an Organised Performance and Governed Communication

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This section develops three lenses for analysing how suffering becomes legible, governable, and valuable: (1) theodicy and religious organisation as historical architectures that normalise suffering; (2) biopolitics and necropolitics as regimes that distribute exposure to harm, and (3) Bourdieu's fields and capital as a model of struggle over legitimacy and resources. These lenses culminate in my concept of *suffering-capital*: the social value that can be produced when hardship is mediated as credible within a field.

Suffering is architected into communities

Whilst discussing the social mechanisms of suffering, many theorists have included the role of religion when reviewing the phenomenon. This is partly due to the role religious ideologies play in maintaining core structures of social order through collective experience and rule-setting (Bourdieu 1977; Weber, 1993; Kippenberg, 2011; Adair-Toteff, 2016; Bourdieu, 2020). Theodicy is the religious acknowledgement that there is undeserved suffering and evil in the world. This problem holds a fundamental challenge to all religions that perpetuate a deity, as it provokes the question: why would an all-powerful god allow such suffering? Adair-Toteff (2016) suggests that 'virtually all of the religions of the oppressed peoples were religions of salvation – and the more the people were oppressed, the more powerful was their hope of salvation' (p. 170). This idea suggests that through the regimen of religious doctrine, suffering has been socially accepted as part of life's journey towards a better destination. This concept satiates both those living through suffering and those observing it. Indeed, 'In contrast to the noble and privileged people who have no need for salvation religions, they hold a special place for the poorer and ''negatively privileged" people' (Adair-Toteff, 2016, p. 170). In this way, stratifications of suffering create distinct milieux of social responsibility and entitlement.

As religion accommodates suffering, it codifies behaviours that constitute civic responsibility and culture. Speaking of Max Weber's sociology of religion, Wilkinson and Kleinman (2016) claim 'one of Weber's major achievements lies in bringing a measure of sociological understanding to bear on how people's encounters with problems of suffering are liable to inform the wider dynamics of social and cultural change' (p. 113). Where these organisational processes that facilitate shared notions of suffering serve to construct

virtuous social functions through compassionate agreements, it should also be considered to what extent these processes manipulate and define our understandings of suffering, and, how these definitions may influence the governance of suffering particularly, as suffering can occur 'not only during the course of a disease but as a result of its treatment' (Cassell, 2004, p. 44). This matters for my argument because organisational doctrines not only offer meaning for suffering but they also prescribe who may legitimately claim it and how. Where religious doctrines once offered moral explanations for suffering, modern states and institutions have come to manage it as a matter of governance. This shift marks the move from theodicy to biopolitics, from divine order to bureaucratic and medical regulation of life and death. This matters for the thesis because the organisation of suffering does not disappear with secularisation, rather, it changes form. Where religious doctrines historically structured the legitimacy and meaning of suffering, contemporary institutions increasingly structure the recognisability and eligibility of suffering through bureaucratic, clinical, and media regimes.

The governance of suffering

If social life is saturated with moral feeling (Wilkinson and Kleinman, 2016), suffering becomes a strategic object for governance. Foucault's (1978) biopolitics names how institutions optimise and regulate life, and Mbembe's necropolitics extends this to the orchestration of death (2019). Between them lie regimes of suffering that normalise unequal exposure to harm. These regimes act in conjunction with the facilitating of life and the facilitating of death to secure dominance. To see Mbembe's theory exercised, the historical actions of the British empire provide us with terrible examples of how regimes of suffering can destabilise populations, leaving them vulnerable to manipulation (Elkins, 2005; Fanning, 2013; Tharoor, 2018).

The logic of sovereignty illustrates how regimes of suffering are rationalised in contemporary politics. Appeals to "taking back control" in recent British political discourse, for example, frame sovereignty as a moral necessity while leaving vague the concrete forms this control entails (Rone, 2021). Such ambiguity conceals what Mbembe (2019, p.66) identifies as sovereignty's ultimate expression, that is, the power to decide who may live and who must die. Read in this light, sovereignty rhetoric aligns with biopolitical and necropolitical logics that sort populations into those whose suffering is rendered visible and actionable, and those whose suffering is disavowed. The production of a 'world of

undesirables' (Mbembe, 2019, p. 38) is therefore not an abstract theoretical claim but one embedded in the everyday language of national politics.

Mbembe's (2019) account of sovereignty constructs a stark divide between a Western "us" and a dehumanised "other," whose suffering is disavowed. Han (2018, p. 12) extends this by showing how neoliberal globalisation institutionalises exclusion through the banopticon[1]-style surveillance, systematically identifying and expelling those deemed unfit for participation. Taken together, these perspectives highlight how suffering is not only produced within national regimes but also embedded in global neoliberal orders. Here, suffering functions both as a mechanism of exclusion and as a consequence of systemic rationalisation, confirming Wilkinson and Kleinman's (2016, p. 114) observation that modern rationalisation is at once a cause and a product of social suffering. Therefore, we must investigate these rationalised structures of order. Through evaluating the formation of these structures, we can begin to build understandings of the different roles that take part in the experience of suffering.

Foucault's (1980) dispositif refers to networks of institutions, rules, and architectures that sustain power. Bourdieu complements this with 'fields', which he describes as relatively autonomous arenas with their own stakes and rules, within which actors struggle over capital (2020). *Habitus* is the term he uses to name the embodied dispositions shaped by trajectories across fields. These fields provide space for different forms of power to be exalted, and the nature of an individual's experience with these fields influences their social reality and, by virtue, their social positioning. To understand the concept of fields, Bourdieu (2020) asks us to imagine 'Sub-universes where different games are played, which have their own rules and structures and reconfigure the external influences. […] The notion of the field thereby becomes a way of defining the notion of relative autonomy' (p. 240). It is through these unique rules that fields perpetuate their power, as those without access to the rules of play stand little chance of victory within the game.

These fields emit and facilitate different types of cultural, knowledge and social capital, all of which inform the tastes, interests and dispositions of the individuals exposed to them.

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[1] *Banopticon* is Didier Bigo's (2008) term for a mode of contemporary security governance in which surveillance works primarily through profiling, risk scoring and data-led sorting to decide who is permitted mobility and rights and who is restricted, excluded or rendered suspect. Rather than disciplining everyone equally (as in the classic panopticon), the banopticon targets selected "risky" populations, producing differentiated access, intensified monitoring, and forms of administrative exclusion through routine, networked security practices.

The sum of these discriminations collaborates to constitute social milieux based upon agreements and disagreements, a concept Bourdieu termed *habitus*. In this way, fields of power directly influence *habitus* and therefore shape, manipulate and enforce stratifications of privilege within society. Despite this, 'fields are relatively autonomous from the space surrounding them' (Bourdieu, 2020, p. 237). To understand the importance of this, we can look to an example of a courthouse or a prison, both of which are institutions of the legal field, yet these institutions may be situated in physical environments that are distinctly lacking in power. If fields distribute power through specific forms of capital, then suffering itself can be understood as one such resource. The following section develops this idea, proposing *suffering-capital* as a way to conceptualise how hardship and its expression acquire social value and circulate within moral economies.

Suffering-capital

Where Bourdieu teaches us about the importance of capital in societal order, his definition is expansive in that it includes, beyond economic commodities, the idea that knowledge, information, culture and social experience all conspire to generate important value when they are embodied by individuals (Richardson, 1986, p. 18). I use *suffering-capital* to mean the socially convertible value accrued through the performance, narration, or proximate management of suffering. Therefore, using this theory of *habitus* and field as a framework, we can build an understanding of how suffering is itself structured into the mechanics of our social order. As discussed, regimes of suffering are evident in the governance of populations at both local cultural levels and national or global levels, but, through the lived experience of suffering, the knowledge of suffering, the culture of suffering and the social nature of suffering, we must also view suffering itself as a distinct type of social capital. This capital navigates a moral economy where 'what is involved in this economy is not goods and services, but values, such as fairness or honour, and affects, such as indignation or compassion' (Fassin, 2020, p. 218).

To illustrate how suffering may generate social value through performance and recognition, it is useful to consider how hardship has been publicly displayed across history. In Monty Python's (1967) *Four Yorkshiremen* comedy sketch, four successful men proceed to outdo one another not with current accolades but with exaggerated hardships ('We drank out of a rolled-up newspaper…'). The humour exposes a counterintuitive logic, that narrated hardship can function as status. The escalation of the conversation takes this increasingly competitive communication of suffering to extremes, where each man performs their

experience of suffering, detailing greater and more horrifying levels of hardship. Where the described hardships and the men's relationship with them are quite ridiculous, the sketch still outlines a contrary and little-explored aspect of suffering; suffering as a valued commodity, irrespective of the desirability of the experience. This idea differs from the previously mentioned notion that those who are negatively privileged are most closely connected to future benefits of salvation (Adair-Toteff, 2016); rather, it proposes that certain negative experiences of suffering are perceived to have a form of social capital in the present.

Across history, suffering has been staged and exchanged as value in different fields. Public performances of suffering that create social capital are not a new phenomenon; they have been documented throughout history. A notable example of this dates back to the 5th-10th centuries with the stylites. These were people who exiled themselves to lives of painful exclusion, where they'd live for months or even years at a time up high on top of pillars. They would endure the weather, and their bodies would often atrophy during the process. Stylites would be visited by citizens who would climb ladders to bring them food, during which they'd ask them questions about important matters of society. Some stylites gained widespread notoriety, such as Daniel the Stylite, and it is suggested that 'such men as Daniel could exercise considerable influence in secular affairs because of their reputation for outstanding sanctity and their relative accessibility' (Collins, 2010, p. 77). These ascetic displays converted endurance into moral authority and influence, an early instance of suffering being transformed into symbolic power.

Where ascetic suffering produced spiritual prestige, secular contexts also found ways to aestheticise or commodify hardship. The example of the 18th-century garden hermits reveals how suffering could be staged as spectacle and pleasure. In elite secular contexts, proximity to suffering itself became a status symbol, and conversely, association with performances of suffering can also manufacture social capital. In the eighteenth century, it became fashionable for the wealthy to build grottos on their land for the purpose of housing an ornamental poor person. These people were called 'garden hermits', and they were impoverished and forlorn. These hermits would be visited by parties of local dignitaries for entertainment. On discussing the history of garden hermits, Campbell (2013) relays that 'many visitors to the gardens respected the figure of the hermit as an embodiment of the ideals of solidarity, retirement, and pleasing melancholy' (p. 2). In this way, we can see that the most fortunate derived pleasure from the suffering of garden

hermits. Where hermits were traditionally the remit of religious practice, garden hermits were secular and evolved in conjunction with the fashions of landscape design (p. 217). Accordingly, an expression of status in society was wedded to the notion of social capital gain through both proximity to suffering and the ability to hold power over those suffering.

In contemporary societies, this conversion of suffering into value persists, albeit through different media. The relationship between celebrity, charity, and affective display continues to turn compassion into symbolic capital. Since the late 20th century, this phenomenon has been better demonstrated through examination of the association between celebrity and charity. Lousley (2014), when exploring the act of charity-giving and social status, found that 'social distinctions remain closely intertwined with performances of feeling, which is a legacy of the culture of sentiment itself' (p. 9). She continued to state that

> The expression of love and sympathy for others not bound by kinship or dependency relations (as in feudalism) developed as an English cultural norm with the emergence of the bourgeoisie and the rise of mercantile capitalism and the sentimental novel (p. 9)

With this premise, performances of reactions to suffering can propagate status and swell the capital of the performer. Ibrahim (2022) supports this theory and suggests that 'Trauma as a site of consumption and the everyday is about relocating its moral economy through its reproduction of social relations and the configurations of power' (p.1). With this notion, both the consumption of the spectacle of suffering and the mediation/remediation of the phenomenon must be viewed as part of the infrastructure of hegemony and of the regimes of suffering.

These historical examples prepare the ground for a clearer theoretical distinction between social capital and what I call *suffering-capital.* While Bourdieu's (1986) concept of social capital emphasises the resources and advantages that accrue through social networks, *suffering-capital* operates according to a markedly different logic. Social capital presumes a pre-existing set of social ties that can be mobilised for influence, reputation, or opportunity. It is fundamentally relational and its value lies in the durability of trust, reciprocity, and mutual obligation embedded within networks of association. By contrast, *suffering-capital* does not derive from who one knows but from how experiences of adversity are mediated, recognised, and valorised within particular social fields. This difference matters. Social capital is generated through positive forms of association and trust, whereas *suffering-capital* is generated through negative experiences such as illness,

poverty, bereavement, or trauma. Once articulated and rendered visible, these experiences can themselves become resources of legitimacy and authority. Where social capital is converted into power through reputation, exchange, and reciprocity, *suffering-capital* is converted through recognition, such as testimony, the performance of pain, or even mere proximity to suffering can provide symbolic value, creating moral authority or eliciting solidarity. In this way, *suffering-capital* is embedded in a moral economy rather than a networked one, drawing its value from audiences who acknowledge the legitimacy of suffering and respond with empathy, indignation, or care. *Suffering-capital* should therefore not be treated simply as a subset of social capital. It is a distinct form of value production, one that operates less on reciprocity and more on recognition; less on trust between equals and more on the unequal dynamics of visibility, legitimacy, and mediation. In short, while social capital concerns the resources embedded in relationships, *suffering-capital* concerns how hardship itself is performed, circulated, and socially validated in ways that generate symbolic influence and reshape social hierarchies.

Analytically, *suffering-capital* is observable in the practices through which hardship is made legible to an audience and becomes convertible into other forms of advantage or access. It can be accumulated through testimonial labour (posting, narrating, documenting, and evidencing), through the circulation of credible idioms (clinical language, biomedical references, recognised symptom categories), and through collective endorsement within community settings. It can then be converted, unevenly and field-dependently, into resources such as legitimacy, attention, solidarity, epistemic authority, or leverage in encounters with medicine, welfare, or media. Crucially, *suffering-capital* also has costs: the labour of producing credible accounts can intensify exhaustion, expose people to harassment or disbelief, and incentivise forms of visibility that flatten complexity within moral economies of recognition (Fassin, 2020, p. 218).

Mediation, Media Power, and the Sociology of Suffering

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Having argued that social agreements around pain and hardship often rely on physical and linguistic performances, it is imperative to understand the communication processes through which suffering is socially validated and recognised. As Fuchs (2020) reminds us, ‘neither societal nor individual being are things-in-themselves, but exist only through mediation, i.e. through societal relations’ (p. 85). Communication technologies increasingly act as gatekeepers to the narratives of those who suffer. Suffering never appears in social life untouched; it is always mediated, and the ways in which experiences of pain and hardship are communicated and recognised depend on the institutions and technologies that frame them. Media systems play a decisive role in this process, shaping whose suffering is seen, how it is interpreted, and whether it is legitimised or ignored. In the following section I make three claims: (i) legacy media gatekeep suffering; (ii) digital platforms reconfigure testimony and commodify affect; and (iii) mediation is constitutive, not neutral. The implications of these arguments will be explored further in the literature review that follows in Chapter 2.

Media as Gatekeepers to Suffering

Legacy media have long acted as the principal gatekeepers through which suffering becomes visible to society. As Chouliaraki (2006) argues, suffering is staged within media frameworks that render it a spectacle. Spectators are interpellated as witnesses or voyeurs, making them active participants in processes of othering (Chouliaraki, 2006, 2013). Just as stylites or garden hermits performed suffering within curated landscapes for their audiences, legacy media frame suffering into theatrical formats designed for consumption.

In competitive economies of attention, media treat testimonies of suffering as a distinct content genre. Ibrahim (2022, p. 69) observes that visual media in particular 'produce their own modes of meaning or morality.' Chouliaraki (2006, p. 37) extends this point, describing mediation as an 'information exchange' that thematises spectators as actors within the spectacle. Because suffering indexes moral order, control over visibility is political; it decides whose claims enter public life and under what frames (Lousley, 2014).

This dynamic resonates with broader debates in media theory. Habermas (1989) famously conceptualised the public sphere as founded on rational-critical debate. Yet, illness

narratives and testimonies of suffering resist such rationalist ideals, foregrounding embodiment, affect, and vulnerability. Media systems, therefore, act not only as channels of circulation but as arbiters of legitimacy, deciding whether experiences of suffering can enter public life as credible forms of communication. The implications of this gatekeeping role will be developed further in the literature review, but first, it is necessary to consider how these dynamics may be transformed by digital landscapes.

Digital Landscapes and the Sociology of Suffering

The rise of digital platforms requires that the sociology of suffering take cyberspace seriously as a site of investigation. Couldry (2010) argues that media systems shape the very possibility of voice. Online environments expand access to visibility, allowing sufferers to bypass traditional gatekeepers. For those whose communicative practices are marginalised, such as disabled people or those with contested illnesses, the potential to narrate their experiences online can be transformative. However, digital publics differ significantly from Habermasian ideals. Papacharissi (2015) shows that they are structured not by rational deliberation but by affective flows. Suffering circulates through hashtags, viral posts, and emotional intensities. This dynamic can mobilise solidarity and empathy, but it also risks reducing suffering to ephemeral spectacle, quickly displaced within algorithmic feeds.

Illouz (2007) introduces further complexity with her account of emotional capitalism. In neoliberal societies, emotions are deeply entangled with markets of consumption and self-improvement. Illness narratives online often circulate not only as testimony but as commodified content within economies of wellness and lifestyle branding. Visibility may empower sufferers, but it simultaneously integrates them into logics of consumption, responsibilisation, and commodification. Digital infrastructures, therefore, reshape the conditions of recognition. They generate both new opportunities for marginalised voices and new vulnerabilities tied to algorithmic governance and market logics. For the sociology of suffering, cyberspace is not simply another channel of communication but an essential terrain of inquiry that reconfigures recognition, legitimacy, and solidarity. These shifts, however, also point toward a deeper claim: mediation itself is never neutral, but constitutive of suffering as a social reality. For conditions like ME/CFS, this means the same infrastructures that enable voice also incentivise formats (brief, affect-intense, algorithm-friendly) that can flatten complexity. Further consideration will be given to this in the upcoming literature review.

Mediation as Constitutive, Not Neutral

Taken together, these perspectives highlight a central claim: mediation technologies are constitutive, not neutral. Legacy media enforced frames that often delegitimised certain illnesses while spectacularising others. Digital media, in turn, open possibilities for testimony but within infrastructures that commodify affect and reward visibility through engagement-driven logics. This view resists techno-optimism, which treats the internet as an emancipatory space of unmediated voice, and techno-pessimism, which reduces platforms to exploitative machines of capture. Instead, it recognises that mediation actively shapes the social reality of suffering. To describe mediation as constitutive is to acknowledge that recognition is inseparable from infrastructures of communication. Testimonies gain legitimacy only through the broadcast networks, feeds, and algorithms that render them visible. These infrastructures filter and aestheticise suffering, creating hierarchies of recognition. Visibility, far from being a neutral process, is always patterned by media logics and embedded in wider systems of power.

The politics of suffering in contemporary societies, therefore, cannot be separated from media infrastructures. Recognition of suffering is contingent on mediated regimes of visibility, which decide not only what is seen but how it is framed and interpreted. Mediation is not merely a channel; it is the terrain on which empathy, legitimacy, and justice are organised or denied. Understanding mediation in this way provides the foundation for the literature review that follows, where the implications of media power for the governance and recognition of suffering will be explored in greater depth.

The sociology of suffering must attend closely to media power as a constitutive force. Legacy media operated as gatekeepers, staging suffering as spectacle and embedding it within moral economies of spectatorship. Digital media reconfigure these dynamics, providing sufferers with new opportunities for voice while entangling them within economies of affect, attention, and commodification. At stake is not just how suffering is communicated but how it is constituted as a social reality.

The implications of this argument extend beyond the present discussion. The forthcoming literature review will examine in greater detail how these dynamics of media power and mediation have been theorised, and how they shape the communication, recognition and governance of suffering. Throughout the thesis, I therefore treat platforms and news systems as actors that co-produce what counts as suffering. These theoretical debates

come into sharp relief when examined through a concrete case. The experiences of people with ME/CFS offer a compelling example of how suffering can be both silenced and rearticulated through mediation. The following section introduces this illness and traces how its legitimacy has been constructed, contested, and negotiated across medical, political, and media fields.

ME/CFS as the population focus of this study: Illness Background and Controversy

To ground these theoretical concerns in a specific case, this thesis focuses on the experiences of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). ME/CFS is an exemplary case of delegitimised suffering whose recognition has depended on mediation within legacy medical and media frameworks. Investigating how people with ME/CFS use digital landscapes to articulate, share, and negotiate their suffering offers a way to examine the possibilities and limitations of mediation in practice, and to explore how recognition and solidarity are organised in spaces beyond traditional gatekeepers.

My interest in ME/CFS emerges from both my own experience with the illness and how it sheds light on the shifting terrain where bodies, knowledge, and politics intersect. In 2009, following a viral infection, I was diagnosed with ME/CFS and became bedbound for eighteen months, unable to speak, move around my home, or perform basic cognitive or physical tasks. I remain affected, though to a far lesser extent. This experience has made me aware of how patients live in conditions of profound precarity. I argue that ME/CFS is not only a contested illness but also a biopolitical formation: a site where medical authority is unsettled, where patients construct alternative circuits of information and treatment, and where the terms of care and legitimacy are renegotiated through digital life.

What is ME/CFS?

ME/CFS is a chronic systemic disease that leads to neurological, immunological, autonomic, and energy metabolism dysfunction (AlMuhaissen et al., 2023, p. 1119). It is characterised by symptoms of extreme fatigue that do not improve with rest, along with a range of other symptoms such as muscle pain or fibromyalgia (widespread pain and tenderness in the body), cognitive impairment (“brain fog”), sleep disturbances, and post-exertional malaise (PEM), which is the worsening of symptoms after physical or mental exertion. Historically, medical bodies have used various labels to describe the condition, most notably Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, SEID and ME/CFS. Any person of any age, gender, or ethnicity can develop ME/CFS; however, the illness is most prevalent among women, with 75+% of those diagnosed being female (Shepherd, 2022, p. 16). The exact cause of the illness is unknown; however, ‘Infection, genetics, and environmental factors, including trauma, are the most commonly discussed etiologies of

ME/CFS, and infection has long been debated as one of the triggers since the initial outbreaks' (Lim and Son, 2018, p. 5). In recent years, the link between viral infection and ME/CFS has been increasingly explored, with links made with BDV, parvovirus B19, Coxsackie B virus (Jae-Hyun et al., 2023) and COVID-19 (AlMuhaissen et al., 2023).

There is currently no known cure, and very few people recover fully. Most patients are unable to return to full-time employment; 40% are unable to work at all, and the illness can severely impair daily activities and quality of life (Vink and Vink-Niese, 2019). Estimates suggest that ME/CFS affects over 250,000 people in the UK, with around 25% severely affected and therefore housebound or bedbound (Institute of Medicine, 2015; NICE, 2021). A growing body of studies has demonstrated that the functional status and quality of life of people with ME/CFS are as great or greater than that of other chronic illnesses or health conditions. Nacul's (2011) research found that 'ME/CFS is disabling and has a greater impact on functional status and well-being than other chronic diseases such as cancer' (p. 402). Kingdom et al. (2018) found people with ME/CFS to be as disabled as those with multiple sclerosis. Both Michel et al. (2015) and Eaton-Fitch et al. (2020) found that the health-related quality of life of individuals with ME/CFS was significantly impaired across all domains. To be clear, highlighting these findings is not to prioritise the suffering of those with ME/CFS above others, but rather to situate the illness as a condition that is chronic and enduring, despite the scepticism that surrounds it. Indeed, irrespective of these findings, scepticism about the severity of the illness persists, and treatment protocols are contentious, making understanding the historical framing of the illness important.

Historical framings of ME/CFS

In 1955, 292 (mainly female) staff members from the Royal Free Hospital in London became ill. Out of these, 255 individuals were hospitalised. As a result of this outbreak, the disease was named myalgic encephalomyelitis in 1956 in an editorial published in *The Lancet.* At this point, myalgic encephalomyelitis was an acknowledged legitimate illness, however, it later became contested. In 1970, without ever seeing a patient, doctors McEvedy and Beard reviewed the notes from the outbreak. They concluded their findings in The British Medical Journal, in which they suggested 'there is little evidence of an organic disease affecting the central nervous system and that epidemic hysteria is a much more likely explanation' (McEvedy and Beard, 1970, p. 7), a perspective they reasoned by the disproportionate number of female patients that became ill. A recent study has revisited the data from the Royal Free outbreak, and their evaluation found that 'ME/CFS is an

organic disease and repudiates the hypothesis of it being a psychosomatic illness' (Underhill and Baillod, 2021, p. 8). A further review by Waters et al. (2020) found that the outbreak fit the SIR disease model, supporting the views of senior medical staff working at the Royal Free at the time of the outbreak, which also contested McEvedy and Beard's findings (Compston et al., 1970). These doctors argued that the majority of the residential staff were female and suggested that if there were contamination in the hospital, it would primarily affect women. They also highlighted evidence of contamination that McEvedy and Beard (1970) had omitted from their paper. Despite these refutations, links between ME/CFS and hysteria or female neuroticism still persist (Murray et al., 2019), and treatment protocols continue to promote mental health interventions, such as exercise and talk therapies, instead of biomedical treatments or investigations, despite comprehensive reports from the patient community that exercise worsens their symptoms. This early psychologising frame shadows subsequent policy and media responses.

Despite the increasing evidence of a biomedical cause for ME/CFS, in 2011, the UK's Department for Work and Pensions (DWP) funded a study at Queen Mary University of London to explore treatment options for ME/CFS based on the assumption that the illness resulted from a combination of unhealthy mental attitudes towards wellbeing and deconditioning caused by inactivity. This study is commonly referred to as the 'PACE trial'. The results of the PACE trial labelled ME/CFS as a psychosocial illness treatable with cognitive behavioural therapy (CBT) and graded exercise therapy (GET), a protocol that requires patients to progressively increase their physical activity over time (White et al., 2011). As a direct result of the trial, these protocols became the only treatments offered to people with ME/CFS in the UK.

However, people with ME/CFS and their carers were widely sceptical of this study, due to extensive reports of patients experiencing a worsening of symptoms after GET. These reports of exercise causing harm are also supported by research; Van Oosterwijck et al. (2010) observed that patients with ME/CFS experienced a worsening of symptoms even after minor physical exertion, while other studies have found that this post-exertional worsening can last for weeks (Lapp, 1997). There is also evidence suggesting that patients with ME/CFS have an exertion threshold, beyond which symptoms worsen and health declines (Black and McCully, 2005). A patient successfully took Queen Mary University of London to court by using a Freedom of Information Act request to access the raw trial data (BMJ, 2016). Subsequent reanalysis showed outcome thresholds were

relaxed to the point that some participants could deteriorate and still be classed as ‘recovered’ (Kindlon, 2017, p. 1147), undermining claims for CBT and GET.

Critics argued that the original results were misleading and that these treatments could harm some patients, a view supported by the independent reevaluation of the data. The study has been subject to substantial methodological criticism, including critique of its limited engagement with biomedical evidence (Geraghty, 2016). From a sociology-of-science perspective, the PACE trial controversy also shows how scientific conclusions can be shaped by the dominant assumptions of a field. In Kuhn’s terms, “normal science” tends to consolidate an existing paradigm, meaning that discordant evidence, such as reports of post-exertional deterioration and emerging biomedical findings, may be marginalised until anomalies accumulate and the prevailing framework loses credibility (Kuhn, 1962). This helps explain why disputes over methodology and “acceptable” evidence are not purely technical, but also institutional and cultural. Consequently, these treatment approaches remain highly controversial for the patient community.

ME/CFS charities, communities and many healthcare practitioners argued that the syndication and communication of this study via media, state and healthcare systems caused further harm to patients. According to a research report conducted by the ME Association, which included data from 1428 patients, GET was found to be generally harmful to patients and often caused a worsening of symptoms, as well as severe relapse. Moreover, the report concluded that allowing GET as a treatment protocol was causing additional systemic harm as it fostered the incorrect belief held by some practitioners that ME/CFS is a psychological condition, ’leading to erroneous advice that exercise could overcome the illness if only patients would “push through”’ (ME Association, 2015, p. 5). It should be noted that NICE has recently updated its guidelines to remove GET from its suggested treatment protocol for ME/CFS (NICE, 2021). The NHS has also followed this action and has removed GET as a treatment protocol from its website, stating, ‘Graded exercise therapy (GET) – which aims to increase physical activity levels gradually - is not recommended for people with ME/CFS’ (NHS, 2023).

The history of ME/CFS illustrates how the condition has been framed through biopolitical processes, where state, medical, and cultural authorities exercise power over how illness is defined and managed. The dismissal of the 1955 Royal Free outbreak as ‘epidemic hysteria’ (McEvedy and Beard, 1970) exemplifies how gendered assumptions were used

to delegitimise patients' experiences, despite later evidence confirming biomedical origins (Underhill and Baillod, 2021; Waters et al., 2020). Decades later, the state-funded PACE trial promoted psychosocial treatments, such as CBT and GET (White et al., 2011), despite patients reporting worsening health outcomes (Van Oosterwijck et al., 2010; ME Association, 2015). The dissemination of these findings through healthcare systems and welfare policy demonstrates how biomedical evidence was sidelined in favour of narratives that aligned with state interests in regulating sickness and return-to-work policies (Geraghty, 2016). Therefore, we must consider ME/CFS to be distinctly biopolitical because its treatment and recognition have been governed not only by scientific debate but also by mechanisms of power that discipline patients' bodies, constrain care, and perpetuate systemic harm.

Mediating ME/CFS

Murray et al. (2019) conducted a review of the representation of ME/CFS in English print media between 1998 and 2015. The researchers found;

> Women who were sufferers were depicted as emotionally and psychologically distressed and unstable, childlike and dependent, and emphasis was typically placed on the disruption of the illness to their relationships and social life. In contrast, men were portrayed as physically active and successful before the disease "struck" from nowhere and the physical consequences were foregrounded rather than the emotional and psychological. Such rigid and stereotypical reporting may be alienating for women, and men, who are struggling with CFS/ME and do not identify with or want to identify with the gendered tropes on offer, thus discouraging them from seeking help (p. 901).

The findings presented by Murray et al. (2019) demonstrate how the British print media has portrayed ME/CFS negatively, aligning with other powerful institutions to the detriment of the affected minority community, while using gendered tropes as well as derogatory terms for the illness, such as 'yuppie flu' and 'lazy disease', to support this framed narrative. The authors argue that the media's depiction of the illness echoes a neoliberal agenda, which shifts responsibility onto the individual for their own health. They conclude that this narrative has contributed to the stigma surrounding ME/CFS and has worsened the suffering experienced by those affected (Murray et al., p.839). These media tropes are precisely the kinds of frames digital communities hold the potential to counter or circumvent.

Building on this idea, it is interesting to consider how people with ME/CFS engage with digital environments as spaces where they can exercise greater agency to shape their experiences of illness. Disabled and chronically ill people often establish a 'network of ‘like-minded people’ from their homes' (Ginsburg, 2012, p. 110), and many people with ME/CFS use the internet extensively, often as a means of accessing information about their condition, connecting with others who share similar experiences, and seeking support from online communities (Rogers, 2023). The internet provides a valuable resource for individuals with ME/CFS who may be physically limited in their ability to participate in traditional social activities or access healthcare services in person. Online forums, social media groups, and websites dedicated to ME/CFS are often frequented by individuals seeking information, advice, and validation from others who understand their challenges. Additionally, the internet allows people with ME/CFS to engage in advocacy efforts, participate in research studies, and access telemedicine services for remote healthcare consultations.

When considering the biopolitics of ME/CFS, Karfakis (2018) argues that: 'Assemblages of authorities, knowledges and techniques make CFS/ME subjects and shape their everyday conduct in an attempt to increase their supposed autonomy, wellbeing and health' (p. 20). Karfakis suggests that a dominant characteristic of this conduct is that people with ME/CFS have used digital landscapes to form a collaborative biosocial community with scientists, making them particularly epistemologically well informed about relevant science and medicine. This community sustains independently of established networks of power; however, 'CFS/ME remains trapped between medicine and psychiatry, in an ongoing battle between all the different actors that want to define it for their own interests' (Karfakis, 2018, p.26). This trapping makes this population a relevant and intriguing case study for examining how populations use digital landscapes to protect their well-being and communicate their suffering, even as the patient narrative often contrasts with the narratives of established power.

However, Rogers (2022) argues that

> although symptoms organize the biosocial world of ME/CFS patient activists, impairment ironically also becomes a barrier to the very biomedical recognition they seek. Impairment structures the forms of activism that can occur in the context of seriously limited energy. This limits advocacy efforts, which recursively sustains the incomplete medicalization of ME/CFS’ (p. 413).

Rogers (2022) rightly observes that impairment structures activism. My findings nuance this by showing how ME/CFS communities develop strategic, low-energy communicative practices that do political work precisely because of impairment constraints. To this end, examining the online communication and community practices of this community through the lens of a framework that views suffering as both necessarily a communication genre and necessarily a biopolitical phenomenon is a compelling and justifiable approach.

If we accept that this population experiences tremendous amounts of suffering that established fields of power have exacerbated, their perspective is especially relevant when considering the use of digital platforms to mitigate the politicisation of their suffering. With this notion, ME/CFS is a critical site for studying mediated suffering because recognition is persistently unstable and sufferers must continually negotiate credibility across medicine, media, and government fields. Digital practices offer routes to testimony and community while also exposing patients to platform logics that can flatten, commodify, or contest their claims.

Research Problem, Aims, and Questions

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Research Problem

This thesis addresses how delegitimised suffering is made visible, credible, and actionable through digital mediation. For people with ME/CFS, whose illness has often been doubted or psychologised, digital environments become key sites for producing testimony, building collective vocabularies, and negotiating recognition. The aim is not to measure whether digital practices "work" in a simple instrumental sense, but to analyse how they operate as social practices that generate identity, community, and forms of capital while positioning sufferers within broader fields of power.

Research Aims

The study is guided by the following aims:

1. Examine how people with ME/CFS use digital landscapes to communicate suffering.
2. Analyse how these practices shape identity, community, and epistemic/biopolitical capital.
3. Explain how practices interact with, resist, or reproduce fields of power.
4. Contribute to theory on suffering, care, disability, and media power.

Research Questions

In order to meet these aims, the study is guided by four research questions:

1. How do people with ME/CFS communicate and mediate suffering through digital landscapes?
2. In what ways do digital practices contribute to community, identity, and epistemic/biopolitical capital?
3. How do these practices position sufferers within wider fields of power and regimes of suffering?
4. How do people with ME/CFS seek to depoliticise or repoliticise their suffering online, and what, if any, are the implications of this for recognition and care?

Theoretical Positioning

I integrate Bourdieu's field/*habitus* framework with biopolitical accounts of governance to analyse how digital practices convert suffering into (or block) forms of capital within specific fields. The theoretical framework combines Bourdieu's notion of *habitus* with a focus on biopolitics and regimes of suffering. As Costa et al. (2018) remind us, Bourdieu's

conceptual framework was intended to reconcile practice and theory through method. *Habitus*, seen as a system of dispositions formed through embodied histories, provides a useful lens for exploring how people with ME/CFS navigate digital landscapes. It allows for analysing how new practices, such as sharing treatment protocols or developing new terminologies, emerge as collective dispositions formed within digital environments. Critiques of *habitus* have been taken seriously in this research design. Gerrans (2005) and King (2000) question whether *habitus* risks objectivism or overlooks agency, while McCall (1992) argues that Bourdieu underplays the role of gender in shaping dispositions. These critiques are particularly relevant given that ME/CFS disproportionately affects women. This makes gendered *habitus* central to understanding which communicative practices gain credibility in ME/CFS spaces. Bourdieu's later work (2001) on gendered *habitus* and McCall's (1992, p. 836) framing of *habitus* as a 'powerfully elaborate conceptual framework' for understanding gendered social relations provide important grounding for this study. Wacquant (2013) further develops *habitus* as a methodological tool, proposing criteria that emphasise synchronic connections, diachronic trajectories, and experimental immersion. These insights have informed the longitudinal and netnographic design of this project, which seeks to observe dispositions as they emerge and evolve within digital fields.

Alongside *habitus*, this thesis draws on biopolitical approaches to suffering. As Lindell (2015) notes, media practices are always situated within fields of power, where resources and dispositions are contested. Digital landscapes do not simply provide neutral spaces for expression; they also constitute regimes of visibility and invisibility, in which suffering is validated, silenced, or politicised. By combining *habitus* with an analysis of biopolitical power, the study is able to address both the micro-level practices of sufferers and the macro-level structures that shape their possibilities.

Contribution

This thesis makes contributions across four interrelated fields. In the sociology of suffering, it develops an account of how delegitimised illness is mediated digitally, emphasising that suffering is not only embodied but also communicative and relational. By foregrounding the experiences of ME/CFS sufferers, the research demonstrates how suffering is collectively negotiated and reframed in ways that challenge existing hierarchies of legitimacy. This helps extend the sociology of suffering beyond institutional and clinical sites, into the digital everyday. In media and communication studies, the thesis contributes to ongoing debates

about media power by situating digital communication within Bourdieu's field theory. Lindell (2015) argues that media practices must be understood relationally, as struggles over capital and position. By analysing ME/CFS communities' digital practices as forms of symbolic struggle, the research illustrates how delegitimised groups can use media not only to resist exclusion but also to generate new epistemic resources. This reframes media power as lived and contested within specific digital fields.

In digital ethnography, the study contributes methodologically by combining netnography, illness journals, and interviews in a longitudinal design. Hine (2000) and Kozinets (2019) conceptualise online ethnography as immersion in virtual cultures, but this study adapts these frameworks for a chronically ill population, adding journals to capture temporal embodiment. The design demonstrates the value of multi-method, patient-centred ethnography in capturing both the immediacy and temporality of digital suffering.

Finally, in illness and disability studies, the thesis advances understanding of how people with ME/CFS articulate identity, negotiate care, and form epistemological communities. McCall's (1992) critique of Bourdieu reminds us that gendered and embodied dimensions of *habitus* matter deeply here, given the disproportionate impact of ME/CFS on women. By centering patient-led digital practices, the research challenges biomedical and policy frameworks that have historically marginalised this population, contributing to broader debates on chronic health conditions and disability, legitimacy, and the politics of care. In bringing these contributions together, the thesis addresses Stiegler's (2013) provocation about the conditions under which therapeutic knowledge can be elaborated and transmitted. It shows that digital landscapes are not merely spaces of expression but also of epistemic innovation, where delegitimised populations generate curative, resistant, and nourishing forms of knowledge.

Methodological Overview

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A qualitative, interpretivist design

I adopt a qualitative, interpretivist design combining netnography of Facebook forums, illness journals, and semi-structured interviews over eighteen months. The aim is to understand how meanings are produced and how practices sediment into dispositions. As Denzin and Lincoln (2011) argue, interpretivist research recognises that social reality is socially constructed, contested, and embodied, requiring sensitivity to nuances and contradictions. Qualitative methods are especially well-suited to illness contexts because they allow for attention to narratives, metaphors, and practices that cannot be simply reduced to numerical indicators. Conrad and Barker (2010), in their work on the social construction of illness, emphasise that conditions such as ME/CFS are influenced as much by cultural interpretation and legitimacy struggles as by medical diagnosis. To explore this, the study was carried out longitudinally over eighteen months. This extended period enabled the observation of participants' reflections and practices as they evolved, were reaffirmed, or shifted, ensuring that findings reflected enduring dispositions rather than brief trends.

Bourdieu (2000) reminds us that *habitus* is itself a product of long-term sedimentation, while Burgess, Marwick, and Poell (2018) caution that digital cultures are also shaped by rapidly changing trends, making temporality a critical aspect of analysis. To achieve this, the study integrated three complementary methods of data collection: netnography, illness journals, and semi-structured interviews. Netnography traced practices and meanings within digital environments; illness journals provided temporal and embodied insights; and interviews facilitated depth and reflexivity. This triangulated design ensured a nuanced understanding of how experiences of illness are produced, lived, and reflected upon across contexts and time.

Positionality: the researcher's role

Finally, the researcher's positionality must be acknowledged. Having lived with ME/CFS since 2009, the researcher had both privileged access to communities and an embodied understanding of the illness experience. Coffey (1999) argues that the 'ethnographic self' is not a bias to be erased but an integral part of the research process. Shared experience facilitated rapport and trust, but it also raised risks of over-identification. To mitigate this, the study employed double coding, grounded interview prompts in participants' journals

rather than researcher assumptions, and maintained a reflexive stance throughout analysis. This positionality, rather than undermining validity, strengthened the research by situating it within the lived realities it sought to understand, while retaining critical distance through structured methodological procedures. Together, netnography, illness journals, and interviews offered complementary perspectives on how suffering is mediated in digital environments. Netnography traced practices and discourses in their natural settings; journals recorded embodied and temporal experiences; and interviews highlighted depth, reflexivity, and voice. Designed with ethical care and grounded in reflexive positionality, this methodological framework provided a strong way to capture the complexity of digital suffering as an embodied, relational, and political phenomenon.

Thesis Structure

This thesis is structured as follows.

- Chapter 2, Literature Review, theories of mediated suffering and digital visibility.
- Chapter 3, Methodology, methods and ethics.
- Chapter 4, Findings and discussion: Treatment discourse evolution in ME/CFS online communities.
- Chapter 5, Findings and discussion: ME/CFS as an epistemic/biopolitical community and forms of capital.
- Chapter 6, Findings and discussion: Engagements with external fields (medicine, policy, media).
- Chapter 7, Conclusion and discussion: synthesises implications for recognition, care, and disability frameworks.

The next chapter reviews scholarship on mediated suffering, visibility, and platform power, situating this study within debates about recognition, credibility, and algorithmic governance. It develops the theoretical foundation for analysing ME/CFS as a case where legitimacy is continuously negotiated across media, medical, and policy fields.

CHAPTER 2: LITERATURE REVIEW

Introduction

This chapter traces the mediation of suffering from the era of mass broadcast media to the networked structures of cyberspace and, finally, to the digitally embodied experiences of disabled communities. It argues that the forms of visibility and compassion once organised through editorial institutions have not disappeared; rather, they have been reconfigured through algorithmic and participatory logics. Across these transformations, the moral economies that govern whose suffering becomes intelligible endure, even as they now operate through metrics, data flows and digital habitus rather than newsroom gatekeeping.

The chapter unfolds in three parts. First, it examines how legacy media constructed suffering as spectacle and cultivated compassion through distance, staging publics as witnesses rather than participants. Second, it analyses how cyberspace redistributes communicative power while commodifying attention, reworking older hierarchies of visibility through platform infrastructures, algorithmic ranking and the datafication of emotion. Third, it investigates how disabled communities navigate these conditions through the cultivation of digital habitus, practices of self-representation and care, and the uneven politics of technological inclusion.

Read together, these sections treat digital mediation as an ambivalent environment in which the same infrastructures that enable recognition and care can also intensify extraction, misrecognition and exclusion, a tension later theorised through Stiegler's *pharmakon*. In doing so, the chapter positions digital landscapes as what Stiegler (2011) calls metapharmacological environments. These technologies can simultaneously heal and harm, emancipate and exploit, offering solidarity and visibility while intensifying extraction and misrecognition.

In this chapter, I also use *suffering-capital* as an analytic to trace how communicated hardship becomes socially convertible value under different media regimes. In legacy media, *suffering-capital* is shaped through editorial selection, spectacle, and managed distance. In platformed environments, it is shaped through ranking systems, metrics, and attention economies that reward particular idioms of legibility (brevity, affect-intensity,

visuality). For disabled communities, *suffering-capital* is both enabled and constrained by digital *habitus* and by uneven access to assistive and accessible technologies. This framing clarifies how the same experiences can gain credibility, solidarity, and epistemic authority in one field while being discounted or exploited in another—an ambivalence later synthesised through Stiegler's pharmakon.

From Mass Mediation to Platform Power

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This section explores how legacy broadcast media have mediated suffering and, in doing so, shaped public compassion, moral sentiment and political attention. It considers how editorial institutions have controlled visibility and framed suffering as a consumable spectacle, inviting emotional engagement while maintaining social distance. Drawing on theories of mediation, visuality and compassion, the discussion highlights how traditional media systems have both organised and distorted our encounters with suffering. This analysis establishes the groundwork for the following section, which turns to the emerging dynamics of social media and cyberspace to examine how new technological logics may reconfigure these processes.

Mediation: Distancing reality and meaning

In my introduction, I argued that the mediation of suffering has long served as a primary means through which societies organise moral sentiment and political attention. In legacy broadcast systems, communicative power has been concentrated in the editorial institutions that decided which suffering was made visible and how it should be framed. While it was previously discussed that garden hermits were constructed as spectacles within designed landscapes to be visited by the wealthy for entertainment, the mediation of suffering bears some comparison. In the mediation of suffering, distress is transformed into a spectacle that is carefully staged within an architected media environment and presented for theatrical consumption by audiences. Positioned as witnesses rather than participants, viewers are invited to observe and emotionally engage from a distance. In doing so, they become implicated in a mediated process that reinforces separation between themselves and those whose suffering is represented, subtly contributing to the othering of people who are living the experience (Chouliaraki, 2006; Chouliaraki, 2013).

These processes also establish the conceptual foundations of what this thesis terms *suffering capital*, the conversion of communicated pain into moral and symbolic value within systems of mediation. Through mediation, suffering becomes increasingly disconnected from reality and meaning. As time and space are distorted and manipulated, the link between all those involved in the spectacle and the individuals who are suffering is stretched. Chouliaraki (2006) describes the technologies involved in these processes as paradoxical, as she argues that 'the role of the media […] simultaneously establish[es] and undermin[es] the immediacy of suffering for the spectator' (p. 37). We particularly see this in action with televised humanitarian aid campaigns, which ask audiences to react with

immediacy to a crisis via a prerecorded message from a celebrity in situ with the catastrophe. It is undeclared, but the audience is aware that the celebrity is no longer at the scene and that some considerable time has passed since this spectacle was created. This pantomime rendition of suffering, which sacrifices accuracy in favour of increased audience engagement, is increasingly blended with cultural forms such as comedy, sport, and music. Examples of such blended content in UK media are programmes such as *Sport Relief*, *Comic Relief* or *Band Aid*. These additional genres collaborate to minimise the risk of audience fatigue and to enable the survival of the genre of suffering. Analytically, this shows how legacy media sustains compassion by blending suffering with entertainment, producing recognition through managed affect while also reshaping what counts as "communicable" suffering within a broadcast moral economy. As previously established, our understanding and acknowledgement of suffering manifest through communication. Mediation and remediation perpetuate knowledge and understandings of suffering, yet they simultaneously shape these understandings according to the agendas of the communication industries.

Architected compassion

Concepts of *visuality* and *gaze* are central to understanding how media construct and communicate experiences of suffering. *Visuality*, as Mirzoeff (2011) explains, refers not simply to what is seen, but to the social and political conditions that determine who has the right to look, who is made visible, and who remains unseen. It is therefore a system of power that structures the field of vision itself. The *gaze*, by contrast, describes the power relations embedded within acts of looking. For Mulvey (1975), this operates at the level of representation, where visual culture positions the viewer and the viewed within particular ideological hierarchies. Foucault's (1977) conception of the gaze adds an institutional dimension to this, showing how visibility functions as a mechanism of control in modern societies, in which to be seen is also to be subjected to regulation and judgement. Applied to the mediation of suffering, these frameworks reveal how media technologies and practices produce asymmetrical relationships between those who are represented and those who observe. Legacy media constructs the suffering subject as an object of visibility, inviting audiences to look upon pain from a position of distance and moral superiority. As Chouliaraki (2006) observes, this creates a carefully managed encounter in which spectatorship is framed as compassion, yet ultimately maintains the separation between those who see and those who are seen. Hoijer (2004) similarly notes that such visual frameworks often reproduce Eurocentric moral codes, transforming compassion into a

performative display of benevolence rather than a mutual ethical engagement. In this way, *visuality* and *gaze* are not merely descriptive tools but reveal the operations of power that underpin the mediated spectacle of suffering.

Arguably, in the UK, these presentations take a Eurocentric or Americanised frame (Hoijer, 2004; Ibrahim, 2022), although it should be noted that where these frames are often aligned, in current times, they are more fractured and diverse due to the fast-changing political landscapes of the European continent and the controversies of the current wave of politics from America. Hoijer (2004, p. 513) argues that

> In Western politics there is a growing focus on human suffering in relation to distant crises and wars, so too in the media and among citizens in general. Global compassion is considered to be morally correct in the striving for cosmopolitan democracy, and the international community condemns crimes against humanity.

What Hoijer asks us to consider is the primary importance of eliciting compassion as a characteristic of the mediation of suffering. Without this, the experience is unfulfilled, and the result would be a failure of communication. Indeed, the drive to provoke compassion holds such importance that it is wedded to fundamental values such as democracy and decency. This, however, requires layers of editorialising deception and distortion, as it is often those architects of power who promote ideas of democracy and decency who play convincing roles in orchestrating and maintaining hardship in the first place. Ibrahim (2022) argues that this editorialisation occurs largely because suffering is presented not as an enduring and inevitable consequence of ingrained power inequalities, but rather as an event that we can use as a social coming together. She makes clear, however, that this 'singular event-based model is not only disruptive of historicity but is distortive for its ability to dismiss and overlook the imperial and colonial hegemony of trauma inflicted through conquest and colonization of the lesser Other' (p. 69).

Ibrahim’s articulation emphasises the power of media to frame experiences in alignment with other fields of power and to shape narratives in conjunction with their objectives. Having argued that media is itself a bespoke field of power which uses its technologies to define communication, we must accept that media is also intrinsic to other fields of power which harness media technologies to coexist together in a state of intercorporeality. Hoijer (2004) agrees with this notion, arguing that media is the primary mechanism through which people experience the spectacle of suffering, the delivery of which serves the primary

purpose to elicit the complex emotional and philosophical motivation that is compassion. She argues that the characteristics of legacy media, both manipulate audiences to elicit compassion but also create direct lines of communication between other organisational bodies and fields of power, stating;

> The discourse of global compassion is situated at the intersection between politics, humanitarian organizations, the media and the audience/ citizens. The media may be seen as an intermediate link between the level of social situations, in which audiences' interpretations and responses develop, and humanitarian organizations and politics (p. 514).

Here, she makes clear that the characteristics of media make possible a responsive dialogue between audiences, humanitarian organisations and political power, without direct communication necessarily occurring between these separate groupings. Arguably, this can yield positive outcomes and a fast-track process for creating awareness and influencing change. We can look at recent examples, such as the footballer Marcus Rashford's media campaign for the British government to provide free school meals for hungry children, to see evidence of how mediated communication can harness the momentum that direct communication, in this case between hungry children and the British state, may not have managed (Oxtoby, 2022). During this instance, the message fanned compassion, and political action was developed in concurrence with this media event. Read through *suffering-capital,* this illustrates how mediated visibility can convert hardship into political leverage, showing one route by which high-attention framing within cyberspace can become actionable.

However, other collaborations can just as powerfully diminish compassion for vulnerable populations. A notable example of this is the 'war on woke' whose mantra has become successfully pervasive in British society. When reviewing the war on woke as a collaboration between the media, celebrities and the current right-wing ruling political order, Cammaerts (2022) found that the abnormalisation of social injustice was central to the message. He maintains that this

> abnormalisation is achieved by strategically instigating moral panics and creating a false sense of crisis with a view to bedevilling social justice struggles as politically deviant, dangerous, sinister, insidious, evil and an imminent danger to British society. This is subsequently coupled with the assertion of a new common sense that normalises what social justice politics aims to contest, expose, and push back against. In addition to this, a self-asserted victimhood, that is, from a position of

> dominance and privilege, is expressed; reversing the perpetrator into a victim and turning the victim into a perpetrator (p. 11).

Cammaerts's findings regarding this campaign are particularly troubling in their drive to fundamentally change the social role of compassion. Here, we see the priorities of compassion reversed from an emotional act that cares for others to an act that prioritises the individual bearer's own claim to social care, irrespective of need.

Having discussed compassion as a fundamental characteristic of the sociology of suffering, the implications of such an assault on social agreements regarding the value of compassion should be investigated. What Cammaerts describes here goes beyond the act of othering those most vulnerable in society; rather, it is defining with certainty these 'others' as enemies, towards which there is a moral obligation to be combative and to act without empathy. This indicates a marked shift in normative expectations surrounding compassion and entitlement, where we can observe, in praxis, media power's ability to collaborate with political power to mutate the sociology of suffering. This case sharpens the claim that media–political collaboration can reallocate compassion by reframing dominant groups as victims, reorganising whose suffering is treated as legitimate and whose is positioned as morally undeserving.

The problem of agency

The mediation of suffering by definition delivers an abstraction from those living suffering, and in this way, mediation will always be problematic in its effectiveness to define and relay the narratives of the vulnerable. Through this process of abstraction, there is a consistent diminishment of the voice of both those very same people and of those whose suffering has been omitted from the media's chosen focus altogether. As Champagne contests,

> When marginal or disadvantaged groups attract journalistic attention, the effects of mediatization are far from being what these social groups could expect since the journalists, in this case, have a particularly significant power of construction so that the production of the event is almost totally out of the control of the people concerned' (Champagne, 1999, p. 49).

Processes of mediation rely on distortions of time and proximity to those suffering by using manipulations of technologies. To create this spectacle, a stage and workforce are engaged to perform and host the phenomenon, some of whom may hold little or no

relationship to the suffering being mediated or remediated. This processing holds the characteristic to marginalise those living the experience of suffering, bringing with it questions of consent and agency for those being depicted.

When discussing changes in the doctor-patient relationship, Cassell (2004) notes that major transformations of this social contract began in the 1960s. These were in conjunction with the mediation of major events of social change, such as the Vietnam War, widespread European turmoil and a decline in power for the Catholic Church. Arguing that these changes gave birth to a new wave of individualism, he notes a correlation between individualism and the way patients take part in their own care;

> They want to take part in decisions formerly reserved for the doctor; they demand choice in therapy and have high expectations as to outcome. These expectations have been nourished by the media and the exploitation of medical achievements by medicine itself in its quest for public support (p. 24).

What Cassell highlights here is that despite a collaboration between both medical and media fields of power, individualism has facilitated an environment (in the Western hemisphere) where patients can exercise greater agency when it comes to their treatment.

Indeed, the mediation process of selling a better experience of ill health has created aspirations of entitlement, birthing the idea that diminished suffering is achievable via purchase. Studies have shown both an increase in funding and an increase in awareness of illnesses when they are mediated (Corbett and Mori, 1999). This highlights the potential for mediation processes to raise awareness, increase investment to combat medical-based suffering and to empower those suffering to play more active roles in their experience. However, if we accept that media power coexists with other fields of power, the authenticity of narratives of suffering should be evaluated for manipulation.

Having discussed earlier in the introduction, charity-giving as a generator of social capital (Lousley, 2014) and as a measure of a moral economy (Ibrahim, 2022), it has become increasingly important to consider the role of celebrity within this construction. It is a contemporary phenomenon that celebrities, i.e., expert performers, have been cast in lead roles in the theatre of corporate communication. This change runs in tandem with the rise of celebrities from powerless to powerful elites, a rise that has 'contributed to transforming the governance of poverty as well as the premises of public action in the west'

(Chouliaraki, 2013, p. 78). Indeed, Chouliaraki argues that it is this partnership between celebrity and humanitarianism that 'brings into focus the inherent theatricality of humanitarianism as an arrangement of separation between those who watch at a distance and those who act on the spot upon human suffering' (p. 79). She concludes that it is

> the hyper-emotionalization of the moral relationships of humanitarianism that displaces a focus on suffering and its causes onto a focus on celebrity and her or his publics, in line with a post-humanitarian sensibility. What these emerging properties throw into relief […] is a major limitation of contemporary humanitarianism: its over-reliance on the authenticity of celebrity which breaks down the function of the theatre as moral education, and, may, ultimately reproduce a narcissistic solidarity obsessed with our own emotions rather than oriented towards action on suffering others (p. 79).

This notion raises two problematic implications for the agency of those suffering. The first is simply a matter of numbers: the larger the cast involved in the performance of suffering, the more diminished the voice of those suffering. The second and perhaps most important challenge is that when celebrities are cast to lead the narrative of suffering, they are often unsophisticated or lacking in expertise. The celebrity voice, by its nature, is often the loudest, leaving little space for alternative considerations or perspectives. Together, these hierarchies of narrative-making facilitate a reality in which those suffering are most commonly outnumbered and demoted within their own story. Such a demotion, or even excommunication from the storytelling process, maintains milieux of suffering, as it is well accepted that language can shape ideology and create power (Fairclough, 2001).

While celebrity-promoted humanitarian communication can effectively build awareness between civilians and governance fields (Castells, 2009), it is important to consider that a celebrity's lack of expertise and authenticity on humanitarian issues may lead to a disconnect between humanitarian organisations and the publics they aim to reach. Where these practices may be lacking in ethical integrity due to their distance from genuine or meaningful ethnographic interactions with those suffering (Fassin, 2011), what is maintained is that this relationship continues to endure as an important mechanism within the moral economy, trading in both values and affects. Fassin (2020, p. 220) highlights that during the course of all

> humanitarian action, whether in cash via donation or in kind via assistance, it is generally expected that the person who receives the gift will express gratitude to acknowledge the generosity of his or her benefactor. Contrary to what is often

> thought, there is therefore an exchange—moral sentiments in return for goods or services—but it is asymmetrical and may even be regarded by the person aided as a way to comfort the unequal social order by rendering it morally acceptable. This explains why receivers may express resentment instead of gratefulness, thus provoking in turn, among donors, frustration, anger, or what is sometimes called compassion fatigue. […] In all cases, it reinforces the disparity between the giver and the receiver.

With this understanding of the role-play among cast members in the mediation of suffering, it is evident that financial and educational benefits may emerge. However, these benefits are potentially and frequently neither directed nor managed by those suffering. Indeed, the theatre of suffering may be configured with minimal connection to the realities of those whom it professes to help.

Summary

Legacy media has long acted as an architect of distance, mediating suffering through carefully staged spectacles that both reveal and obscure the realities of those who suffer. Its defining characteristics lie in editorial control, distortion of time and space, and a theatrical presentation that turns suffering into a consumable experience. Through this framing, audiences are invited to bear witness from afar, participating emotionally without ever engaging materially. Televised charity events and celebrity-led humanitarian campaigns exemplify this process, blending moral appeal with entertainment to sustain engagement while eroding authenticity. In this system, compassion functions less as a genuine moral response and more as a managed affect, orchestrated through the collaboration of media institutions, politics, and humanitarian organisations. The result is a moral economy in which empathy is both commodified and constrained, and where the voices of those experiencing suffering are continually displaced by the louder, more authoritative narratives of others.

As communication technologies evolve, the frameworks through which suffering is mediated also shift. The emergence of social media and networked digital spaces introduces new patterns of visibility, interaction and control that both challenge and replicate the hierarchies of legacy systems. What changes is not the existence of moral economies of suffering, but the mechanisms through which they operate: where broadcast systems largely centralised visibility and moral sentiment in editorial institutions, cyberspace distributes visibility across platforms, algorithms and users who both witness and perform suffering.

This shift should not be read as a linear transition from legacy media to cyberspace, nor as the replacement of one system by another. Legacy media remains embedded within the infrastructural, economic and cultural logics of digital platforms, while platformed communication increasingly borrows the dramaturgy of broadcast spectacle. The next section, therefore, turns to cyberspace to examine how participatory architectures and computational logics reconfigure the mediation of suffering, and how older hierarchies return in new forms through metrics, data flows and algorithmic governance. This legacy architecture is directly relevant to ME/CFS because contested illness is especially vulnerable to institutional framings that psychologise, sentimentalise, or delegitimise suffering. These broadcast histories form the background conditions patients later confront online, where credibility must be rebuilt against inherited tropes and sceptical publics.

Suffering in cyberspace

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What is cyberspace?

As communication technologies have evolved, the frameworks through which suffering is mediated have transformed alongside them. The emergence of social media and networked digital spaces has introduced new modes of visibility, interaction and control that both challenge and replicate the hierarchies of legacy systems. While traditional broadcast media concentrated moral sentiment in the hands of a few, digital platforms disperse communicative power across vast, interconnected networks of users, algorithms and automated systems.

Web 2.0 has long been used to describe aspects of the internet that enable user-generated content (UGC). This environment is defined by three key characteristics. The first is the opportunity for audiences to participate and interact with media, allowing individual and personal stories to become shared and accessible data. The second is an openness that enables freedom of expression to thrive, and the third is the creation of a networked environment. Much has been written about the Habermasian qualities of Web 2.0, with scholars suggesting that these communication technologies create spaces that democratise communication by improving access to information and facilitating participation in debate and action (Papacharissi, 2010; Murthy, 2011; Castells, 2015).

The web has since evolved beyond the framework of Web 2.0 through the integration of artificial intelligence (AI), which fosters more intelligent and personalised online experiences. AI now drives recommendation systems, chatbots, content creation and predictive analytics, making the internet increasingly adaptive and responsive to individual users. This progression is often described as a bridge towards Web 3.0, characterised by AI integration, decentralisation and the semantic interlinking of data, which enable more intelligent and adaptive forms of communication (Berners-Lee et al., 2001; Aghaei et al., 2012; Gan et al, 2023; Hassan et al., 2023).

As terminology within the literature varies and is often used interchangeably to describe these evolving digital landscapes, I will, for clarity, refer to this environment as *cyberspace*. This term encompasses the participatory and networked characteristics described by Web 2.0 scholars while also capturing the ongoing computational, decentralised and AI-driven developments that shape the modern digital terrain. While “Web 2.0” and “Web 3.0” are

contested and inconsistently used across scholarship and industry discourse, I use cyberspace here as a pragmatic umbrella term for contemporary networked communication shaped by participatory production, platform infrastructures, and AI-driven curation.

Having established cyberspace as both participatory and computational, the analysis now moves from definition to consequence. The sections that follow proceed in three steps: first, they examine how platforms redistribute gatekeeping through algorithmic curation and echo-chamber dynamics; second, they explore the ethical shift from prescribed spectatorship to participatory digital witnessing; and third, they connect these developments to the attention economy, where visibility and emotion are converted into value. This sequence clarifies how the mediation of suffering changes shape without losing its underlying moral and political stakes.

From editorial to echo chamber

Having outlined cyberspace as a participatory and data-driven environment, this section now considers how algorithmic infrastructures redistribute communicative authority and reshape the visibility of suffering. Theorists of the platform society explain how communication, governance, and the economy are now organised through interconnected digital infrastructures that extract data and curate visibility (van Dijck, Poell and de Waal, 2018). Platformisation has integrated functions once spread across various institutions, such as news, politics, health, and entertainment, into corporate ecosystems that structure participation through proprietary code, terms of service, and monetisation channels. However, Helberger (2020) argues that these platform functions are most perilous in their capacity to wield opinion power, influencing public discourse and pluralism by determining the infrastructural conditions of visibility and interaction. In this way, platforms show a structural shift in communicative authority, from broadcast editors who previously curated narratives of suffering to mobilise compassion, to platforms that calculate relevance and allocate rewards through metrics.

This shift is entangled with data colonialism and surveillance capitalism. Couldry and Mejias (2019) theorise data colonialism as the appropriation of human life for extraction as data. Zuboff (2019) names an economic order that collects human experience as free raw data and uses prediction and targeting to drive profit. In such a regime, testimonies of suffering do not merely solicit empathy; they generate data flows that feed measurement,

optimisation and advertising. As previously theorised, suffering produces its own modes of meaning or morality; under platform capitalism, it also produces measurable engagement. Where I have conceptualised suffering-as-communication and *suffering-capital*, it becomes clear how these ideas intersect with platform infrastructures where the genre and value of suffering are transformed into rankable, monetisable assets.

Within this regime, *suffering-capital* becomes quantifiable: likes, shares, and impressions transform compassion into data-driven currency. Indeed, if a core requisition of *suffering-capital* is its visibility, then mechanisms that calculate visibility become pivotal in the economy of suffering. Gillespie (2014) describes algorithms as ‘public relevance engines’ (p. 168), quietly establishing hierarchies of visibility. This represents a new form of gatekeeping, no longer organised by editors' selection but by computational ranking optimised for engagement. In this way, the communicability of suffering is increasingly determined by its performative compatibility with metric cultures. Short, visually striking, affect-intense posts rise to prominence, while complex, slow or fluctuating accounts of illness or hardship sink into obscurity. This does not eliminate agency, but it does raise the cost of complexity, making legibility increasingly dependent on platform-compatible forms.

Scholarship on platform power is divided between accounts that emphasise algorithmic determination of visibility and those that foreground user agency, tactical practice, and counter-public formation. My position treats platforms as structuring conditions rather than total determinants as algorithmic governance shapes what becomes legible and rewarded, but users nonetheless develop practices that negotiate, exploit, and sometimes resist these conditions. This distinction matters for ME/CFS because energy-limited participation intensifies the costs of visibility work while also motivating strategic, low-exertion forms of testimony and care.

Chouliaraki’s paradox re-emerges here in computational form. Media still ‘simultaneously establish and undermine the immediacy of suffering for the spectator’ (2006, p. 37), but the mechanism has shifted. Feeds deliver perpetual immediacy through real-time circulation while undermining ethical proximity by rendering testimony as endlessly substitutable units of engagement. The spectator’s role is maintained, but in playing the part of witness, audiences in cyberspace increasingly become participants in the mechanism that others those who suffer. Under platform governance, this othering is enacted not only through

representational codes but through ranking systems, friction points and commercial priorities that invisibly determine whose pain travels.

Castells' (2013) diagnosis of media power now fully materialises: 'power resides in the communication networks and their owners' (p. 417). Platforms own the conditions of legibility as they decide whether suffering appears, to whom, and with what economic effect. Visibility is commodified, and with it, recognition. The currency is explicit impressions, click-throughs, comments and watch time; even *suffering-capital* becomes operational, as communicated pain accrues value in proportion to its ability to attract and sustain measurable attention.

Tools that create boundaries or subgroups can help subcultures strengthen their *habitus* by shielding them from harmful rhetoric or external hostility. At the same time, these tools can also make spaces opaque where harmful ideologies or radicalisation develop unchecked (Nobel, 2018). A clear example is found in the increasingly common forums of Incels (men who identify as involuntarily celibate), which use moderation tools to exclude wider publics. Sugiura (2021) investigates Incel communities and highlights a 'construction of choice' (p. 110) in which performances of suffering are enacted. These performances depict the loss of the ability to live sexually fulfilling lives, leading to blame that frames the suffering of celibacy as an imposition caused by choices made by women. The suffering described is severe and all-consuming, and the narratives used to overcome this hardship often involve violent retaliation against women.

These performances of suffering, although far removed from previously discussed understandings of legitimate suffering, still reproduce its communicative features through performance and through a medium that fails to distinguish between content genres. They adopt Mbembe's (2019) language of 'a world of undesirables' (p. 38), creating a nuanced form of capital exchanged among participants: a *pseudo–suffering-capital* that maintains the performative and communicative traits of suffering without reflecting the realities that suffering involves, such as diminished power, marginalisation, and imposed hardship. Indeed, the vast majority of incels belong to the dominant population of white, cisgender men of European or North American descent (Sugiura, 2021, p. 108).

In these forums, we see the philosophies of individualism and hyper-emotionalisation combine to produce distorted constructions of reality, detached from wider social

agreements. Yet as these spaces strengthen, their ideas are remediated across multimodal landscapes, and we see ‘Messages and symbolism in mainstream media are appropriated by such online communities to promote their beliefs, whilst their language is increasingly infiltrating common vocabulary, reinforcing misogynistic, homophobic, ableist and racist rhetoric’ (Sugiura, 2021, p. 108). Through this example, the movement from editorial to echo chamber becomes visible. The decline of institutional editorial control does not necessarily herald democratisation; rather, it reconfigures power. Platforms replicate editorial functions algorithmically, shaping which performances of suffering gain visibility and which remain unseen. Participation, in this sense, replaces but does not dissolve hierarchy and we see the editorial returns, dispersed through metrics and networks, as the logic of the “echo chamber”.

This example is not introduced to equate incommensurable experiences, but to illuminate how platform structures can grant visibility and affective reward to performances that mimic the communicative style of suffering. It therefore sharpens the chapter’s central claim that as editorial control declines, hierarchy does not disappear but re-enters through algorithmic selection, community boundaries and metric incentives. With these infrastructural dynamics established, the discussion now shifts from how platforms curate visibility to how users participate in witnessing, and what ethical tensions this produces.

From Prescribed Watching to Digital Witnessing

The following discussion shifts from platform architecture to the experiential and ethical dimensions of visibility, tracing a shift from prescribed spectatorship in legacy media to participatory witnessing in digital culture. In legacy media environments, witnessing suffering has been largely a prescribed act. Audiences were positioned as spectators, consuming carefully framed representations of trauma mediated through editorial control. Newsrooms, documentaries and television reports determined what could be seen and how it was narrated, constructing a moral and affective distance between those who suffered and those who watched. This prescribed watching reinforced institutional authority over narratives of pain, producing a structured and selective mode of engagement.

While such media occasionally invited participation, for example, through charitable donation, advocacy campaigns or other forms of mediated response, these interventions were orchestrated within tightly managed representational and ethical frameworks. Viewers were encouraged to engage, but their participation was guided and constrained

by the moral scripts provided by broadcasters and humanitarian institutions. This produced what Chouliaraki (2006) conceptualises as a spectatorship of pity, where feeling and action were channelled through predefined avenues rather than through open dialogue or collective authorship.

With the rise of social media, these boundaries have eroded. The act of witnessing has shifted from the editorialised transmission of suffering to what might be described as digital witnessing, a participatory practice in which individuals document, circulate and respond to testimonies of harm in real time. The digital interface transforms watching into involvement, blurring the line between observer and participant. Within this networked environment, witnessing becomes both an act of expression and a mode of belonging, producing shared affective and moral communities around suffering.

Wu and Montgomery's (2019) study of the 2015 Tianjin blasts exemplifies this transformation. Examining how Weibo users responded to the disaster, they demonstrate how individuals translate private, sensory experiences into public testimonies capable of challenging official accounts. As they note:

> Witnessing serves the purpose of documenting the course of the accident, breaking news to the distant audience, communicating private experiences, and expressing personal emotions and judgments. However, what makes the performance of witnessing distinct […] is that it demonstrates how social media technologies have endowed individuals with a new form of capital in transforming private sensory experiences into a public testimony that has the potential of challenging the disaster discourse constructed by local authorities and mainstream media and providing a counter-official discourse on social media platforms (p. 689).

This notion of capital directly relates to my earlier theorisation of *suffering-capital,* a form of social and affective value created through communication *habitus* and visibility. I would argue that Wu and Montgomery's (2019) "new form of capital" indeed describes suffering capital, as it explains how individuals gain symbolic legitimacy and visibility by turning personal experiences of crisis into public testimony. In *suffering-capital*, this process extends to the wider economy of affect that circulates via digital platforms. Here, expressions of pain and marginalisation become resources for belonging and recognition, shared among audiences who participate in the witnessing process, showing how visibility acts as a form of capital that rewards communicable suffering and transforms it into symbolic and emotional value within platform cultures.

Similarly, Peng, Sun and Wu (2025) argue that witnessing through social media not only becomes a means of expressing solidarity but also serves political and ethical purposes, cultivating responsibility between witnesses and audiences. Digital witnessing, therefore, operates simultaneously as personal testimony and collective accountability, redistributing the moral and communicative power once held by institutional editors. Prendergast's (2018) concept of moral witnessing deepens this understanding. She suggests that witnessing involves not merely viewing trauma but engaging ethically with it, thereby compelling audiences to reflect on their own implication in others' suffering. In this sense, witnessing moves along a continuum from passive observation to active moral engagement, mobilising empathy, advocacy and, at times, political action.

However, as Carter-White and Doel (2021) note, the authenticity of digital testimony is fraught with ethical and epistemological tension. They describe witness narratives as

> beset by an epistemological paradox – wherein the physical and emotional proximity of witnesses to appalling violence and suffering simultaneously grants them a unique authority to bear witness but also compromises their ability to recall and convey events in a clear and coherent way (p. 456).

This paradox is intensified online, where testimony circulates at speed and scale, often stripped of context. On platforms such as Instagram and TikTok, suffering risks becoming aestheticised or commodified, transformed into an affective spectacle optimised for engagement rather than understanding. This dynamic is evident across multiple digital movements. Survivor testimonies within the #MeToo campaign (Gilmore, 2019), digital witnessing of racialised police violence (Richardson, 2020), and critical witnessing during the COVID-19 pandemic (Browne, Banerjea and Bakshi, 2020) illustrate how social media enables collective witnessing while simultaneously exposing witnesses to scrutiny, co-option and emotional exhaustion. These examples demonstrate that while social media expands the means of testimony, it also entangles witnesses within systems of visibility and attention that commodify suffering.

The phenomenon of vicarious or cumulative witnessing further complicates this picture. Anderson, Morton and Trejo (2022) show that continuous exposure to racial violence through digital media imposes significant psychological and emotional burdens on Black youth, framing this process as cumulative witnessing that shapes both identity and well-being. Similarly, Hidayah, Nova, and Sari (2022) emphasise the dual potential of digital

platforms for young audiences: to connect through shared experience yet also to internalise distress, blurring the line between witness and victim.

At the extreme end of digital witnessing lies the phenomenon of swatting, in which false emergency reports are made to dispatch armed law enforcement to a target's location. Swatting exemplifies how visibility and spectatorship can be weaponised, transforming witnessing into a form of digital violence. In the live-streamed environments of platforms such as Twitch and YouTube, swatting becomes a spectacle in which audiences are not only present but complicit, participating in what might be described as voyeuristic engagement. Bareikytė and Makhortykh (2024) discuss how the representation of violence in digital communication enables a form of "inconspicuous witnessing" that reshapes our understanding of media consumption. As they explain:

> Inconspicuous witnessing is not mainly focused on an event or an incident, but constitutes its own emergent conversational dynamic that includes stories, insults, critiques, *pereklychka* practices that persist in the situated channels and change over time. This diversity of digital war witnessing results in the specific formation of inconspicuous war witnessing, where the representation of mass violence goes beyond traditional media platforms or media events and becomes part of everyday digital communication (p. 360).

This observation illuminates the dynamics of swatting, where the boundary between witnessing and participation collapses. Audiences become part of the unfolding event, their engagement amplifying both the fear and visibility of the act. Similarly, Sumiala (2019) explores how digital witnessing elicits emotional and voyeuristic responses through platforms such as YouTube, where spectators derive a thrill from the proximity to fear and violence of the victims of swatting. The interactive immediacy of such platforms fosters a sense of community among participants, blurring distinctions between entertainment, complicity and ethics. The thrill experienced by online audiences reflects a broader cultural shift towards consuming suffering as spectacle, a pattern that renders digital witnessing inseparable from the economies of attention and affect that underpin contemporary media.

Taken together, these studies signal a transformation from witnessing as prescribed watching, structured by editorial authority, to witnessing as digital participation, structured by immediacy, interactivity and circulation. Cyberspace enables new forms of collective sense-making and solidarity, but also reproduces hierarchies of attention and emotion. The digital witness therefore emerges as both empowered and exposed, capable of contesting

dominant narratives of suffering yet implicated in the voyeuristic and often violent dynamics that govern whose pain is seen, shared and believed.

Digital witnessing, therefore, expands the means of testimony while intensifying exposure to scrutiny, co-option and affective exhaustion. These tensions are not only cultural but economic, as witnessing takes place inside platforms that capture time, emotion and engagement as value. The next section, therefore, turns to the attention economy to show how the circulation of suffering is shaped by monetised visibility, and how compassion is reorganised through metrics, competition and algorithmic reward.

From Captive Audiences to Economies of Attention

Building on this analysis of witnessing, this next section investigates the economic foundations of digital visibility, showing how attention itself becomes a form of currency within platform capitalism. The shift from prescribed watching to digital witnessing signifies not only a transformation in how suffering is mediated but also a fundamental reorganisation of the economic and moral foundations that sustain visibility in cyberspace. While legacy media created captive audiences, constrained by the timing of broadcasting schedules and editorial control, social media has reconstituted these audiences into active participants in an economy of attention. A system that commodifies time, emotion, and engagement as tradable resources. The concept of the attention economy was first articulated by Herbert A. Simon (1971, p. 40), who observed that

> in an information-rich world, the wealth of information means a dearth of something else: a scarcity of whatever it is that information consumes. What information consumes is rather obvious: it consumes the attention of its recipients. Hence a wealth of information creates a poverty of attention.

In cyberspace, attention functions as the scarce resource that platforms compete to capture, organise and monetise. Within this order, as Fuchs (2014) argues, platforms operate as sites of digital labour, where users' time, attention and affect are converted into value. The user's temporal and emotional investments are harnessed to sustain the infrastructures of digital capitalism.

Fuchs (2015) further emphasises the intrinsic link between time and matter, noting that 'time is the development of the existence or being from one condition to the next… It is irreversible' (p. 94). In cyberspace, this irreversibility is exploited as users' temporal presence, such as their scrolling, viewing and posting, becomes the raw material of

accumulation. The ‘subsystems of modern society,’ Fuchs writes, each develop ‘specific economies of production, circulation and distribution of power' (2015, p. 98). Within platform capitalism, this economy revolves around temporal extraction by way of the conversion of human attention into measurable data and data into capital. Napoli (2019) reframes this dynamic by describing platforms as marketplaces where visibility is currency and attention the tradable unit. Under this logic, value is not produced through the quality of communication but through its capacity to capture and hold gaze. What was once the captive audience of broadcast media has become the captured attention of digital media, where users voluntarily offer their focus, emotions and time to algorithmic systems that monetise their participation.

Critical communication theorists have examined the social and political implications of this economy. Ylä-Anttila (2020) demonstrates how the attention economy has contributed to the rise of right-wing populism, as platforms privilege sensational and emotive content that drives engagement, thereby amplifying polarising ideologies. Shultz and Karsgaard (2023) similarly observe that in educational settings, attention metrics prioritise visibility and performance over authenticity, transforming communication into a form of public relations rather than pedagogy. Heyman and Pierson (2015) link this commodification to delinguistification and the colonisation of lifeworlds, warning that as attention becomes a commodity, meaningful communication and interpersonal connection risk decline. The result is a culture driven by performance and reaction, where linguistic and emotional expression are absorbed into capitalist circuits of visibility.

This commodification of emotion aligns with Illouz’s (2007) concept of emotional capitalism, where affective life and economic life intertwine. Cyberspace exemplifies this fusion as emotions are measured as success metrics, engagement transforms into labour, and visibility is maintained through affective intensity. Seen through this lens, *suffering-capital* becomes measurable and competitive, and recognition is increasingly distributed according to platform-friendly forms of communicability rather than the complexity of lived experience. As Jenkins (2006, 2020) contends, the rise of participatory culture and convergence media has blurred the boundaries between producers and consumers, turning participation itself into a productive force. However, while Jenkins praises the creative and collaborative potential of convergence, participation in social media is not equally distributed within the political economy. It is shaped by algorithms that reward

frequency, emotional intensity, and shareability, criteria that favour spectacle over substance.

Papacharissi's (2015) concept of affective publics further elucidates this landscape. She describes how digital platforms enable the formation of publics bound by shared feeling rather than shared ideology. These affective formations spread emotional expressions that both unite and divide users, creating what she calls "networks of sentimentality." In the attention economy, affect becomes a form of currency and suffering, outrage, and empathy are all utilised to sustain cycles of visibility and value.

Bhandari (2023) discusses the significance of anti-systemic social movements within these logics, emphasising that activists must navigate capitalist structures of visibility to remain understandable. The political potential of networked activism is therefore limited by the same metrics that commodify it. Zhang et al. (2017) highlight the consequences of this competition, noting that in the attention-driven environment of social media, the value of information is determined by its ability to generate clicks and reactions. Sensationalism often overshadows substance, creating a hyper-competitive communicative space where misinformation thrives because engagement is prioritised over accuracy. These analyses collectively reveal how the attention economy reconfigures moral economies of visibility. Where compassion once operated through prescribed narratives of pity, it is now distributed algorithmically across economies of outrage, empathy and virality. Suffering circulates not only as testimony but as content, which is optimised for metrics, filtered through affect, and measured in impressions. The moral economy of cyberspace is therefore inseparable from its capitalist infrastructure as the visibility of pain becomes a function of its profitability.

The implications of this regime are tangible in the lived experiences of digital participation. As this thesis will explore how people with ME/CFS use cyberspace to mediate their suffering, it is worth considering them here. For individuals with ME/CFS, the platform economy is not abstract but embodied. Communicating suffering online demands cognitive effort, time and emotional exposure as each is a scarce resource under conditions of energy limitation and post-exertional malaise (PEM). Yet platform architectures reward precisely the forms of labour that are most demanding: frequent posting, audiovisual self-documentation and rapid interaction. Participation turns into a trade-off between expression and exhaustion. In this sense, data extraction parallels energy extraction.

Every act of sharing and every supportive interaction is appropriated as engagement data, feeding systems that do not return energy to the user. Suffering testimony circulates as a data object, enriching the platform while depleting the body that produces it (Couldry and Mejias, 2019; Zuboff, 2019). The result is an uneven distribution of *suffering-capital*.

Narratives that conform to platform-friendly tropes, such as dramatic decline or miraculous recovery, gain traction, while those documenting the slow, fluctuating, or invisible dimensions of illness are algorithmically marginalised. The temporalities of PEM clash with the immediacy of cyberspace, revealing how even acts of bearing witness are subordinated to the extractive logics of the attention economy. Ultimately, the transformation from captive audiences to economies of attention reveals the deeper moral paradox of digital capitalism as the very systems that promise voice and visibility also exploit vulnerability, turning suffering into a data-driven resource and empathy into engagement. For ME/CFS communities, these metric pressures intersect with post-exertional malaise and cognitive limitation, making visibility work unusually costly and uneven. As a result, credibility becomes dependent not only on truth-claims but on whether sufferers can sustain platform-shaped communicative labour without bodily deterioration.

The transformation from captive audiences to economies of attention exposes a central paradox of digital mediation, that is, systems that promise voice and participation also extract value from vulnerability. In this environment, suffering circulates as testimony and as content, shaped by algorithmic curation and metric reward. For disabled users, these dynamics are intensified because participation is embodied. It is constrained by fatigue, pain, access needs and uneven technological support. The next section, therefore, turns to disability, *habitus* and cyberspace to examine how disabled communities build forms of digital *habitus* and mutual care while navigating the platformed hierarchies that govern visibility and recognition. These dynamics are best understood as structurally ambivalent, as the same platform affordances that widen participation also intensify ranking, monetisation and affective fatigue. This reflects the pharmacological tensions that shape digital environments as simultaneously enabling and corrosive.

The tensions identified throughout this discussion can be further understood through Derrida's concept of the *pharmakon*. In *Plato's Pharmacy*, Derrida (1981) revisits Plato's treatment of writing as simultaneously remedy and poison, a force capable of preserving knowledge while also weakening memory and truth through substitution. The *pharmakon*,

therefore, destabilises binary distinctions between cure and harm, authenticity and corruption, demonstrating that mediation itself always contains an ambivalent potential. Derrida's reading is primarily concerned with language, writing and representation, showing how communicative forms both sustain and threaten meaning. This is particularly relevant to the mediation of suffering because digital communication similarly operates through paradox: the same technologies that enable testimony, recognition and solidarity can also distort, commodify and exhaust those experiences through repetition, abstraction and spectacle. Chouliaraki's (2006) observation that media simultaneously establish and undermine the immediacy of suffering reflects precisely this pharmacological tension, whereby mediation both connects audiences to suffering and distances them from its lived reality.

Stiegler (2011; 2013) extends Derrida's formulation beyond textuality into a broader political and technological analysis of contemporary media environments. For Stiegler, technologies are never simply emancipatory or oppressive; rather, all transformational technologies possess a pharmacological structure in which cure and poison remain inseparable. He argues that modern technological systems increasingly shape not only communication but also memory, attention, education and sociality itself. This becomes especially significant within digital capitalism, where algorithmic systems organise visibility, affect and participation according to economic imperatives. As Stiegler (2013, p. 19) contends, the misuse of the pharmakon can bypass reflective thought and contribute to the "proletarianization of spirit", depriving subjects of the knowledge and capacities necessary for autonomy. His argument resonates strongly with the present discussion of platform governance and the attention economy, where users' emotional and communicative labour is transformed into extractable value through metrics, ranking systems and data circulation. Equally important, however, is Stiegler's insistence that technological systems also retain the potential to cultivate care, collective intelligence and new forms of social participation. In this sense, cyberspace should not be understood as inherently democratic or inherently exploitative, but as a pharmacological environment whose consequences emerge through the organisation of its social, political and technical relations.

This pharmacological perspective is highly compatible with Bourdieu's theory of *habitus* and field because both approaches reject technologically deterministic understandings of social life. Bourdieu demonstrates that practices emerge relationally through the interaction between embodied dispositions, social structures and fields of power, while

Stiegler emphasises that technological systems actively shape the conditions through which memory, attention and social behaviour are formed. Read together, these perspectives illuminate how digital *habitus* develops within technologically mediated fields that simultaneously enable and constrain action. Platform architectures, algorithmic visibility and assistive technologies do not determine behaviour outright, but they structure the conditions under which symbolic capital, recognition and legitimacy can be acquired. In this way, digital technologies participate in shaping *habitus* itself by influencing the communicative norms, rhythms and possibilities through which individuals come to understand themselves and others. This is particularly important for disabled communities whose participation in cyberspace is mediated through unequal relations of access, visibility and technological support. The *pharmakon*, therefore, provides a conceptual bridge between Bourdieu's sociology of practice and contemporary digital media theory, allowing cyberspace to be understood as a field in which technological systems simultaneously reproduce domination and create possibilities for solidarity, resistance and care.

Disability, *Habitus* and Cyberspace.

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As communication increasingly unfolds within digital spaces, the mediation of disabled suffering has entered a new phase in which online participation itself becomes an act of embodiment. This section explores how disabled individuals and communities use cyberspace to negotiate visibility, belonging, and power through the formation of a digital *habitus*. Drawing on Bourdieu's concepts of *habitus*, field, and capital, it considers how online platforms function as structured spaces that both enable and constrain expressions of suffering. Within these environments, disabled users engage in practices of self-representation, advocacy, and mutual care that redefine traditional boundaries between private pain and public action. The discussion that follows examines how such practices both challenge and reproduce dominant hierarchies of mediation, revealing cyberspace as a contested field of empowerment and exclusion. This section begins by analysing how disabled individuals and groups cultivate digital *habitus* through everyday practices of online interaction and community building.

To keep the chapter's argument cumulative, this section mirrors the chapter's earlier movement from structure to experience. It first considers how disabled users cultivate community norms and boundaries online (digital *habitus*), then examines how these practices translate into public-facing visibility and activism (mediation and awareness), and finally addresses the material politics of inclusion through assistive and accessible technologies. This structure clarifies how empowerment and exclusion coexist across the same communicative field.

Cyberspace: Creating digital *habitus* for disabled populations

This section examines how disabled users actively construct digital *habitus* within online environments that blend community, advocacy, and self-representation. Although early cyberspace was often described as relatively unregulated and normatively fluid, it has since evolved into a more structured communicative landscape where disabled communities are developing their own digital *habitus*. It is important to note that these technology landscapes have evolved to provide tools for citizens to draw and manage bespoke boundaries, such as the private group options we see on Facebook that allow administrators and authors to moderate such spaces. With the increased use of such tools, bespoke communities are actively crafting safeguarding agreements. As such, we can observe more nurturing and supporting habitats of mediation where options of

anonymity, closed spaces for discussions and moderated support networks all help to facilitate broad and enduring communication.

Cyberspace is increasingly providing a vital terrain through which disabled communities cultivate bespoke networks of connection, care and advocacy. Across diverse studies, researchers have shown that social media and online communication platforms facilitate the formation of supportive micro-communities that transcend geographical and physical barriers (Anderson et al., 2023; van Alem et al., 2025). Through activities such as vlogging, blogging and participatory dialogue, disabled users construct spaces of belonging and collective identity that challenge social isolation and marginalisation (Huang and Wang, 2023; Svensson et al., 2024). These networked environments also enable mutual empowerment and activism, allowing disabled people to articulate shared experiences and mobilise around structural inequities (AbouWarda et al., 2024; Wolbring and Ghai, 2024). These practices are consequential because they redefine audience and agency. What was once mediated about disabled people becomes communication by and for disabled communities. In this way, cyberspace operates as both a communicative and cultural field where disabled *habitus* is expressed, affirmed and transformed. The creation of digital *habitus* therefore represents both a continuation and a re-appropriation of *suffering-capital*: disabled communities convert communicated vulnerability into collective knowledge, solidarity, and agency.

Disability scholarship is divided on visibility in that public representation can enable recognition, solidarity, and political claims-making, yet it can also reproduce ableist expectations and disciplinary norms (for example, inspiration tropes and techno-supercrip imaginaries). I treat disabled visibility as structurally ambivalent. It can generate recognition and collective resources, but it can also impose legibility labour and performance pressures that sort disabled subjects into “credible” and “non-credible” identities. This framework aligns with the chapter’s *pharmakon* reading of digital environments as simultaneously enabling and corrosive.

To expand on a particular example, Goldfarb and Armeta (2017) spent time evaluating POS REP, which is an online community of veterans. They leverage these tools to inscribe virtual boundaries, creating a bespoke public. They found 'an important aspect of what POS REP accomplishes is to mediate experiences of vulnerability by providing tools for navigating the public space and establish a connection within an empathetic community'

(p. 174). In Bourdieu's terms, POS REP stabilises a field whose norms and resources are collectively produced, converting vulnerability into social and symbolic capital. Veterans use this group to mediate many mental health, physical health, cultural and financial hardships that they are enduring since returning from national service. Goldfarb and Armeta (2017) argue that it is 'shared vulnerability that creates spaces for independence' (p. 172). Additionally, organisations such as The Amputation Foundation (n.d.) offer weekly online Zoom events that enable their community to meet virtually, share lived experiences, and discuss the everyday realities of disability. These regular gatherings not only provide emotional and social support but also exemplify the development of a shared digital *habitus*, a set of practices and dispositions through which disabled individuals navigate and inhabit online spaces. By fostering collective dialogue and belonging through digital interaction, the Foundation's activities illustrate how cyberspace can become an extension of embodied community, reshaping both social participation and identity formation within disabled culture.

In this way, the multimodal, expansive, and hybrid characteristics of cyberspace are used in conjunction with additional sets of inter-community agreements that moderate access and allow people to share aspects of themselves as they wish, affording anonymity where desirable. Although this may not constitute a public sphere given these restrictions, it does realise a sub-sphere with a culture of compassionate behaviour and productive information-sharing for those who need it. These examples illuminate how disabled communities inhabit cyberspace not merely as users but as agents within a field of power. Through repeated interaction and shared norms, they accumulate social and symbolic capital that reinforces solidarity while contesting the able-bodied assumptions embedded in mainstream digital culture.

In Bimber et al's (2005, p. 382) work, which evaluates collective action in cyberspace, they relay that;

> one of the chief obstacles to human interaction is informational: the discovery of shared interests, shared desires, or common experiences and acquaintances. Technologies that help people identify and overcome these information and communication obstacles can readily facilitate the beginnings of social behaviour.

Digital infrastructures, therefore, address a core informational barrier to collective action by rendering shared experience discoverable; in doing so, they accelerate the formation of a digital *habitus* through repeated, patterned participation. Given its capacity to connect dispersed publics at scale, cyberspace tends to accelerate the circulation of experience

and the rapid formation of shared interpretive norms. As Bourdieu's social and cultural capital is acquired, both consciously and unconsciously, through sociality and passive and/or active media engagement, it is reasonable to surmise that this landscape accelerates changes in *habitus*. Where cultural capital was originally envisaged as a currency of cultural fields of power, embodied capital in social media landscapes has increasingly become less a process of prescription from power and more an act of crowdsourcing. This illustrates a shift from passive media consumption to participatory knowledge production. Yet, as Bourdieu would note, such practices operate within structured hierarchies of power where digital capital can both empower and mislead.

When reviewing the logic of online health activism, Vicari and Cappai (2016, p. 1668) found;

> favouring processes of crowdsourced knowledge production and exchange, digitally networking mechanisms (e.g., Facebook pages or groups, Google+ circles, Twitter accounts or Twitter hashtagged streams) can ease the emergence of personal narratives of illness that become central to generate and strengthen ties within a patient community, produce, share and disseminate patient-generated health epistemic knowledge and create the context for patients' health political action.

Cyberspace invites the media consumer to engage simultaneously as the media producer, an activity commonly referred to as 'produsage', and this act of produsage allows individuals to create knowledge. Internet forums often facilitate procedures of abductive reasoning where citizens work from an abstract concept (such as a question or a theory posed by a user) and they proceed to provide simple and 'common-sense' conclusions to verify that concept. As the consumer becomes producer, produsage fosters rapid crowdsourced sense-making, but it can also normalise 'common-sense' claims without evidential warrants. This can encourage infallible thinking (Popper, 2002). It must then be acknowledged that the produsage and user-generated content (UGC) which maintain these landscapes can manifest *Doxa,* ideological and arbitrary beliefs that are accepted as knowledge despite lacking epistemological validation. Taken together, these studies highlight how collective knowledge production in digital spaces simultaneously fosters connection and generates new epistemic risks, a dynamic that Bourdieu helps us to interpret through the concept of *doxa*.

Where structuralist theories can be deemed to prioritise order, or, more increasingly, computational rationale above subjective agency, Bourdieu (2018) views *doxa* as a combined result of the objective structures of society and the subjective agency of

individuals, which together create our sense of reality. He suggests that it is through this partnership that ‘every established order tends to produce (to very different degrees and with very different means) the naturalisation of its own arbitrariness’ (Bourdieu, 2018, p. 164). In this way, the creation and reinforcement of *doxa* are inevitably pervasive due to largely unconscious processes of manifestation.

Accepting this rationale, social media arguably influences *habitus* by creating and reinforcing knowledge, albeit often heavily subjective. This can increase the voices of those suffering by allowing them to share their lived experiences, their observations and their realities, therefore creating wider agreements of understandings which can expand beyond those individuals suffering and out to wider communities/society. However, despite its potential validity, this type of information communication inevitably lacks rigorous epistemological investigation and is therefore vulnerable to manipulation and misinterpretation. Consequently, while the co-creation of meaning can democratise discourse around suffering, it also exposes disabled narratives to the same algorithmic pressures that commodify attention and emotion, echoing legacy media’s moral economies in new digital forms. For disabled communities, this means that testimonies of suffering can gain cultural traction quickly, yet remain vulnerable to misrecognition when algorithmic curation rewards affect over epistemic robustness.

These dynamics intersect with what disability scholars describe as *supercrip* narratives, which frame disabled people as inspirational figures who overcome impairment through exceptional resilience, effort, or moral fortitude (Barnes, 1992; Clare, 1999). However, ‘supercrip stories never focus on the conditions that make it so difficult for people with Down syndrome to have romantic partners, for blind people to have adventures, for disabled kids to play sports’ (Clare, 1999, p. 2). Such narratives are not novel to digital environments and have long circulated within legacy media, charity campaigns and popular culture, where they individualise disability and obscure structural injustice (Kafer, 2013). However, within cyberspace, these narratives are intensified and reconfigured through platform logics that reward visibility, affect and shareability, encouraging performances of disability that conform to motivational, heroic, or aspirational tropes. As Wolbring (2024) argues, contemporary supercrip representations are increasingly technologised, producing the figure of the *techno-supercrip*, in which “overcoming” disability is read through access to high-status assistive technologies, enhancement imaginaries, and upgradeable bodies rather than through collective or structural change.

Within digital cultures, this shift can sharpen hierarchies within disability communities by amplifying visibility for those whose bodies and devices align with aspirational norms, while marginalising disabled people who are non-enhanced, techno-poor, or whose impairments do not lend themselves to narratives of triumph. While supercrip representations can offer moments of recognition or counter stigma, they are frequently harmful insofar as they reinscribe ableist expectations, reframe suffering as a test of character, and displace attention from the social organisation of disability (Young, 2014; Wolbring, 2024). In this way, digital cultures do not invent the supercrip figure but, rather, embed it more deeply within economies of attention that monetise inspiration while disciplining disabled self-representation.

Mediation of Disabled Suffering and Public Awareness

If the previous section establishes how disabled communities build supportive sub-spheres, this section examines what happens when disability testimony moves beyond those sub-spheres into wider publics shaped by media and state power. Having considered how digital *habitus* forms within supportive networks, the discussion now turns to the public and political dimensions of disabled suffering, examining how online activism reframes marginalisation as structural injustice. Digital platforms have created new arenas in which suffering is not only represented but contested. For disabled populations, cyberspace has become a crucial site through which the experience of marginalisation is made visible and reframed. As Xu et al. (2017) demonstrate, protest-blogging and social media activism can serve as effective forms of tactical resistance against policies and practices that exacerbate vulnerability. Their research highlights multiple instances in which sustained online engagement has compelled corporations and state actors to alter policies that enhance suffering for disabled populations through consistent pressure from online citizens. Here, suffering is reframed from private misfortune to structural injustice through strategic visibility and networked solidarity.

One recent example that underscores this potential is the UK Home Secretary's controversial 2022 proposal to deport refugees and asylum seekers from the United Kingdom to Rwanda without trial or legal process (Patel, 2022). Central to the critique is that disabled refugees are disproportionately exposed to harm through deportation regimes. Recent research consistently demonstrates that a significant proportion of refugees experience disabling conditions, whether physical, psychological, or both, with prevalence estimates ranging from 14 to 60 per cent across contexts (Tofani, 2022; Kaur

et al., 2023; Handiso et al., 2024). Critics of the policy opposed it on the basis of the unfair and unnecessary suffering it would cause potential deportees, many of whom are disabled, either from birth or through the direct effects of the hardships experienced during displacement. Although sections of the British press supported the initiative (Martin, 2022), the policy was initially delayed by legal pressures from the European Court of Human Rights (ECHR, 2022).

Despite mounting legal opposition, the British government persisted in its efforts to mobilise the policy. In response, Freedom from Torture, an international NGO, used social media campaigns to encourage tens of thousands of people to lobby the Spanish airline contracted to deliver these deportation flights. The campaign succeeded when the airline, *Privilege Style*, withdrew from the Rwanda scheme (Freedom from Torture, 2022). This example demonstrates how digital mobilisation can convert visibility into institutional pressure, illustrating a route by which mediated suffering claims become politically consequential even against aligned state and legacy media power.

This use of cyberspace is particularly significant as it opposes both governmental and legacy media power. It illustrates how digital communication technologies can enable citizen-led agendas to influence change and reframe suffering as a matter of structural injustice rather than individual misfortune. Yet, as Van Dijck (2013) reminds us, such instances of apparent democratisation must be critically examined, as 'social media services can be both intensely empowering and disturbingly exploitative; sociality is enjoyed and exercised through precisely the commercial platforms that also exploit online activities for monetary gain' (p. 18). Indeed, these communication technologies increasingly facilitate a sphere of social production that monetises both affect and labour through surreptitious consent (Hardt and Negri, 2019). To this end, where we may observe change following citizen-led campaigning, such events require scrutiny as to the nature of the change, and an evaluation of whether the outcomes, while appealing to citizen populations, may also serve the interests of established powers.

In this regard, Peterson et al. (2019) make an important contribution to understanding the effects of cyberspace on health activism. They note a shift away from communicating the lived realities of suffering towards prioritising publicity and funding, a movement they refer to as 'bio-digital citizenship' (p. 478). This mode of operation correlates awareness to funding, replicating the business model in which brand awareness translates into

economic value. The weakness of this approach lies in its dependency on sustained engagement, as audiences must remain emotionally and digitally invested.

An example of this type of digital health activism is the Ice Bucket Challenge (IBC), a social media video phenomenon designed to draw attention to and raise funds for Amyotrophic Lateral Sclerosis (ALS). Participants filmed themselves pouring a bucket of ice water over their heads before nominating others to participate, with donations encouraged to ALS charities. The challenge reached a vast audience across social media, with Facebook (2014) claiming that 'between June 1 – September 1, more than 17 million videos related to the Ice Bucket Challenge were shared. These videos were viewed more than 10 billion times by more than 440 million people,' including participation by celebrities and politicians.

When evaluating the IBC, Burgess et al. (2018) argued that such phenomena are not merely viral events that flare and fade, but rather they are memes, cultural practices that become part of social life. They observed that 'a number of participants framed the challenge as an opportunity to show a different side to themselves, gain others' respect, and make a mark' (p. 1046). In this way, the communicative exchange often prioritised self-performance and visibility over the original message of suffering. They also noted that taking part in such challenges involves 'weighing the reputational risks of contributing too late in the challenge's life-cycle and producing an excessive performance' (p. 1049). These findings suggest that such online acts are frequently driven by the pursuit of social capital rather than a sustained concern for those affected by ALS. Consequently, the focus on publicity detached the campaign from the lived experience of suffering, resulting in the IBC brand arguably becoming larger than the ALS cause itself. This interpretation is supported by the statistic that 'one in six people in the UK participated in the IBC, but only 10 per cent made a donation' (Burgess et al., 2018, p. 1038). These findings illustrate how spectacular visibility can detach from embodied experience, producing recognition without comprehension and attention without durable support for those living with ALS. This example clarifies how platformed visibility can detach recognition from understanding, converting compassion into performative participation while leaving the underlying suffering only thinly engaged.

While the gamification of activism may have produced a shared cultural experience for many, there is little evidence that the IBC led to prolonged financial support or generated a

deep understanding of the illness's impact on sufferers. This transformation of humanitarian expression into performative engagement reveals how social media can reframe suffering as moments of temporary, consumable compassion, in which visibility substitutes for solidarity. In contrast to the *Freedom from Torture* campaign, which leveraged digital tools to resist structural injustice, the IBC demonstrates how online participation may depoliticise suffering by turning it into a vehicle for self-promotion rather than generating collective moral action.

At the extreme end of this phenomenon, social media also facilitates the performance of suffering in ways that are harmful or fatal. Increasingly, platforms host viral challenges that encourage acts of endurance, self-harm, or danger. A recent example is the Black-Out Challenge (BOC), which encourages participants to strangle themselves until they lose consciousness. This challenge has led to the deaths or long-term suffering of several young people internationally and is far from an anomaly (Paul, 2022). Xian et al.'s (2019) quantitative analysis of non-suicidal self-injury (NSSI) depictions on social media found a persistent increase in such content, while Miguel et al. (2017) similarly concluded that these technologies are relational to NSSI patterns.

While online spaces have long served as outlets for expressions of pain, the gamification of suffering through challenges such as the BOC marks a shift in how pain circulates and gains social value. Participatory systems that reward engagement, for example, through "likes," "shares," and "follows", amplify content that provokes emotional response, including self-destructive acts. As a result, perceptions of the social value of suffering are increasingly shaped by platform algorithms and audience interaction rather than by the authenticity of lived experience. Although a meme such as the BOC is distinct from posts depicting NSSI, where the latter often seeks to communicate distress rather than to invite a dare, both are absorbed into the same attention economy. In each case, audiences participate in the performance of suffering, sometimes actively encouraging harmful behaviour. Taken together, these phenomena demonstrate how platform reward structures can incentivise risky or harmful performances of suffering, reinforcing that visibility is not a neutral good but a metric-governed economy with material consequences.

Through these dynamics, cyberspace reveals an evolving culture in which suffering is simultaneously commodified, aestheticised, and contested. Where legacy media once clearly distinguished between news, fiction, and entertainment, cyberspace dissolves such

boundaries, blurring the line between lived experience and performative display. Consequently, the mediation of suffering online becomes both a form of self-expression and a site of competition for attention, altering public understandings of empathy, care, and moral engagement.

Taken together, these cases demonstrate that the mediation of disabled suffering in cyberspace is characterised by tension between empowerment and commodification. Digital platforms have allowed marginalised groups to transform suffering into public testimony and political resistance, yet the same infrastructures absorb these expressions into cycles of attention and affect that reproduce inequality. Online storytelling and activism can thus reframe suffering as structural injustice rather than individual tragedy, but they do so within architectures that monetise visibility and emotion. The challenge lies in sustaining forms of digital communication that amplify disabled voices as sources of knowledge and sites of claim-making, rather than subsuming them into the spectacle and metrics that platforms monetise.

Access, Assistive Technologies and the Politics of Inclusion

This chapter's final discussion moves from visibility and activism to the conditions of participation itself, asking, who can meaningfully enter these spaces, sustain communication within them, and convert online engagement into durable recognition? This final section explores how assistive and accessible technologies mediate participation itself, showing that inclusion in cyberspace depends not only on access but on design ethics and technological embodiment.

People with disabilities often face physical limitations, making mobility and even leaving their homes difficult. This highlights the potential for cyberspace to enhance communication, particularly benefiting those with additional communication vulnerabilities, as assistive artificial technologies provide valuable tools for improving interaction across various online platforms. These technologies, including speech recognition, natural language processing (NLP), and computer vision, are inherently transformative. For example, speech recognition systems convert spoken language into text, greatly assisting individuals with speech impairments as well as those with energy-limiting conditions, while NLP advancements result in more effective text-to-speech solutions for those who are visually impaired, thereby improving access to information and overall online communication (Eziamaka et al., 2024; Zdravkova et al., 2022). Additionally, such tools,

which utilise AI, can help users with motor impairments type more efficiently through predictive text technology, which can aid the speed of interaction and enhance opportunities for real-time interaction within the communication process (Eziamaka et al., 2024). Additionally, the personalisation capabilities of these technologies further enhance communication for users with disabilities. Algorithms that adapt to individual needs enable AI-driven systems to tailor communication tools, creating bespoke usage. This includes customisable settings in mobile technology, providing greater autonomy during online interactions (Wald, 2021; Barua et al., 2022).

One of the presented benefits of generative AI tools is that they enable users to create web content without advanced technical skills. However, while empowering, these tools also raise concerns about accessibility and usability. Guo et al. (2020) highlight the need for more inclusive algorithms, with programming led by the users they seek to serve, rather than by programmers who make assumptions without lived experience of disability. The need for such development is also supported by Palmer and Oswal (2024), who evaluated the effectiveness of accessible technologies, such as screen readers, and found them to be less comprehensive and accessible than manufacturers claimed. These shortcomings underscore the need for both technological and media literacy when these technologies are deployed, as they are not always straightforward to use, thereby creating new barriers to access built into the technology itself. What is also highlighted is that those with access to such technologies may be profoundly advantaged over those who do not.

These technologies do more than bridge access gaps; they actively shape how disabled users experience and perform participation online. In this sense, assistive tools contribute to the formation of a digital *habitus*, a set of embodied and cognitive dispositions that develop through repeated engagement with digital environments. This extends Bourdieu's framework into the digital sphere, where embodied dispositions are mediated not only by social fields but by technological affordances. As Ellis and Kent (2017) observe, accessibility is not simply a matter of technical inclusion but of how disabled people inhabit and negotiate media spaces. Through the use of speech recognition, screen readers, or predictive interfaces, users cultivate adaptive practices and expectations that enable them to participate in digital life on their own terms. Yet, when design is restrictive or assumes an able-bodied default, this *habitus* becomes constrained, reinforcing patterns of exclusion and dependence rather than empowerment. In this way, inclusive design does not merely

provide access to cyberspace but also shapes the social and cultural identities that emerge within it.

At the same time, accessibility must be recognised as a digital right, essential for fair participation in modern communication. The way online environments are designed with accessibility in mind reflects the broader politics of inclusion that support cyberspace. As Goggin (2017; 2022) argues, digital inequality is produced not simply by access issues, but by the design of digital environments that privilege certain bodies and marginalise others. Inclusive architectures, such as platforms that emphasise captioning, customisable interfaces, or universal design principles, embody an ethic of shared participation, while exclusive architectures maintain inequalities of power and, as discussed, can potentially create new ones. This situates accessibility within the broader discussion of digital rights and design ethics, where the struggle for equal access to mediated communication becomes a struggle for recognition, autonomy, and justice in the digital realm.

To this end, assistive and accessible technologies, now entwined with cyberspace, do more than facilitate participation; they intervene in the formation of social practice within digital fields. When viewed through a Bourdieusian lens, these tools engage to shape a digital *habitus* that reflects both the constraints and possibilities of mediated life for disabled people. The capacity to navigate, produce, and share within cyberspace becomes a form of cultural and symbolic capital that can challenge dominant hierarchies of communication. However, when accessibility remains uneven or tokenistic, digital architectures reproduce the exclusions of the offline world.

The struggle for inclusive design, therefore, is not simply a matter of technical improvement but of redistributing power within the communicative field. It is within this interplay between technology, embodiment, and social recognition that the politics of digital inclusion and the mediation of disabled suffering are profoundly revealed. Empirically, this underscores that assistive technologies and accessible design are not secondary conditions of participation. They shape who can enter digital spaces, how testimony is produced, and which sufferers can accumulate or convert s*uffering-capital* into recognition and care. For energy-limited conditions such as ME/CFS, accessibility and interface design directly affect the feasibility of sustained communication, community maintenance, and political voice.

Chapter Summary: Mediation of Suffering as Pharmakon

This concluding summary uses Stiegler's pharmakon not to introduce a new strand of literature, but to synthesise the chapter's findings into a single interpretive frame that holds together harm and possibility within the same digital environment. Taken together, these analyses reveal continuity rather than rupture in the mediation of suffering. From the moral architectures of broadcast media to the algorithmic governance of cyberspace, power remains organised around the capacity to frame, circulate and monetise pain. What changes are the mechanisms (editorial, metric, and technological) through which this moral economy operates.

In legacy media, communicative authority was concentrated in editorial institutions that staged suffering as spectacle and fostered compassion through distance, inviting audiences to witness from afar while sustaining asymmetries of gaze, voice and agency. In cyberspace, that authority is redistributed but not dissolved as platforms calculate relevance, allocate visibility through ranking systems, and convert testimony into engagement metrics, such that suffering becomes legible and valuable in proportion to its compatibility with the attention economy.

For disabled communities, these shifts create both openings and constraints. Digital *habitus* offers new forms of collective voice, mutual care, and advocacy, yet it remains shaped by the same logics of attention and visibility that structure contemporary media, including the pressures of performance, the risks of misrecognition, and the unequal politics of access to and use of assistive technology. The chapter, therefore, establishes the conceptual foundation for the empirical analysis that follows, which investigates how users negotiate these tensions in practice and how suffering capital, digital *habitus* and algorithmic power intersect within everyday communication.

This continuity can be read through the heightened distance of contemporary capitalism. Žižek (2014) characterises the power of modern-day capitalism as a regime largely removed from persuasive rhetoric; rather, he describes it as driven by the violent chaos of algorithms. In this way, power is further removed from human concern than ever before. This discussion has elucidated how cyberspace is indeed governed by computational rationalisations which seek the capitalistic agenda of their programmers. However, it has also shown how these technologies may provide shelter from these agendas, allowing

citizens to hijack these technologies to enact humanist agendas, which may thwart or reshape existing processes of mediation, and allow the human experience to have a greater influence upon constructing *habitus*. In this sense, cyberspace bends in both directions: it can amplify personal narratives and shared subjective realities, yet it can also divert the narrative away from original messages and epistemological claims. Anonymity, pseudonymity, and the ability to frame, create or even live alternative identities in cyberspace can cloud narratives around important sociological behaviours, such as suffering, just as easily as they can create environments that bring greater knowledge and understanding to discussions. What appears as democratisation is therefore always vulnerable to capture, distortion, and commodification.

To evaluate cyberspace critically, we therefore need to consider the environment as a pharmakon (Stiegler, 2011, 2013). Stiegler argues that all ‘technological knowledge is pharmacological, that is, it has the ambivalent structure of a pharmakon: it is always at once potentially beneficial and potentially harmful’ (2011, p. 28). He expands this thought to relational digital technologies, such as those that facilitate cyberspace, by terming those technologies ‘meta-pharmacological’. Claiming that ‘they lead to the formalisation and industrial control of transindividuation processes themselves. They thereby raise completely new questions, and they must be understood as transformational technologies — not of matter but of that “material” from which the social fabric is woven’ (Stiegler, 2011, p. 29). Read in these terms, the preceding sections do not describe a simple migration of suffering from one medium to another, but a shift in the pharmacology of mediation: the means by which suffering is made visible and meaningful also become the means by which it is extracted, ranked and repurposed.

Adopting Stiegler’s position allows us to recognise that digital technologies cannot be neatly classified as either emancipatory or oppressive. Rather, they constitute a terrain of metapharmacology, a space in which cure and poison are intertwined. The same infrastructures that extract data, commodify emotion and extend capitalist power also enable solidarity, visibility and collective knowledge among marginalised groups. This ambivalence is central to the chapter’s argument. The legacy spectacle of suffering and the platformed circulation of testimony are both forms of mediated care and mediated control: they can generate recognition and resources, while simultaneously reproducing distance, hierarchy and fatigue. For disabled users in particular, pharmacological tension is not abstract but embodied. Cyberspace can function as a refuge for connection, support

and advocacy, while its architectures of engagement can impose additional burdens of exposure, legibility work, and competitive visibility, especially when participation depends on uneven access to assistive and accessible technologies.

The *pharmakon*, therefore, provides a way to hold together the chapter's core finding: mediated suffering is never simply revealed or concealed, empowered or exploited, but continually negotiated within systems that produce both recognition and harm. Across broadcast and platformed environments, suffering becomes socially consequential through a chain of mediation: (1) experiences are translated into legible idioms (narratives, images, clinical language, affective cues); (2) visibility is allocated through institutional or computational gatekeeping; (3) audiences and communities confer recognition (or disbelief), generating differential credibility; and (4) credibility may convert into resources (care, solidarity, epistemic authority, political leverage), or into (5) extraction (datafication, harassment, fatigue). This mechanism provides the analytic bridge to the forthcoming chapters, which trace how ME/CFS communities negotiate these steps under conditions of contested legitimacy and constrained energy.

This understanding provides the conceptual bridge to the methodological framework that follows. If cyberspace functions as a metapharmacological environment and is simultaneously therapeutic and toxic, then empirical research must be sensitive to both its curative and corrosive potentials. The next chapter adopts a mixed methodology, combining netnography, participant journalling and interviews, to explore how people with ME/CFS navigate this ambivalent terrain. Through examining how they use digital landscapes to mediate their suffering, the methodology seeks to understand lived experiences within this pharmacological environment: where technology becomes, at once, a source of connection, care and knowledge, and a mechanism of fatigue, commodification and exclusion.

CHAPTER 3: METHODOLOGY

Introduction

This study examines how people living with ME/CFS use digital landscapes to communicate delegitimised suffering and negotiate recognition, credibility, and care. It asks how these mediated practices shape identity, community norms, and forms of capital, and how they interact with wider fields of power (medicine, welfare, media, and platforms). The study's objectives are to elucidate how digital environments: (1) are used to share, witness, live, inform, aid, treat, politicise, and govern suffering; (2) reshape advantage and disadvantage in the sociology of suffering; and (3) enable (or constrain) the accumulation and conversion of resources such as legitimacy, solidarity, and epistemic authority.

To address these objectives, the project adopts a qualitative, longitudinal design. It combines netnographic observation of ME/CFS-related digital spaces, participant journals completed over three months, and semi-structured interviews. This multi-method approach captures communication "in action" within online environments while also documenting how participants interpret, evaluate, and narrate those interactions over time. Rather than assessing digital mediation as simply effective or ineffective as a channel for distributing messages, the study investigates how suffering becomes socially consequential through mediated recognition, and how repeated online practices sediment into shared dispositions and norms, analysed through the lens of *habitus*.

Conceptually, the study is oriented by Stiegler's (2011) question of 'under what conditions can therapeutic knowledge be elaborated and transmitted… insofar as it is essentially pharmacological' (p. 28). This frame helps examine when digital environments cultivate curative or nourishing forms of care and knowledge, and when they intensify toxicity, misrecognition, exhaustion, or extraction. The research is therefore exploratory and theory-building and it is inductive in its attention to participants' accounts and emergent patterns, while remaining analytically focused on the relationship between suffering, mediation, and power.

This chapter is organised as follows:

1. Research design and philosophical positioning

2. Fieldwork approach and setting
3. Sampling and recruitment
4. Data collection methods
5. Ethics and safeguarding
6. Data analysis
7. Trustworthiness and rigour
8. Positionality and power relations
9. Limitations

Research Design and Philosophical Positioning

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Epistemological and Ontological Positioning

This research is situated within a critical–interpretivist paradigm, which recognises that knowledge is both socially constructed and shaped by the material and structural conditions of the world in which it is produced (Guba and Lincoln, 1994; Crotty, 1998). Ontologically, it assumes that reality is relational and layered, existing both through and beyond the individual, yet continuously reproduced and transformed through social practice (Bhaskar, 1975). This position aligns with Bourdieu's conceptualisation of *habitus* as both structured and structuring, where dispositions emerge through the interaction of embodied experience and structured social fields (Bourdieu and Wacquant, 1992). In this sense, the social world is viewed as simultaneously objective and subjective, where meaning and structure coexist in a dynamic and generative relationship.

Alongside this, I draw on Stiegler's concept of the *pharmakon* as a guiding interpretive lens for approaching digital environments. Rather than functioning as a standalone ontological claim, pharmakon is used here to foreground the constitutive ambivalence of platformed mediation: the same technical systems can enable connection, recognition, and the circulation of therapeutic knowledge while also intensifying misrecognition, exhaustion, commodification, and exclusion. This assumption is analytically important for a study of delegitimised suffering in digital spaces because it directs attention to how benefits and harms are co-produced within the same infrastructures, and it informs the study's commitment to tracing both curative and corrosive dynamics in participants' communicative practices.

Epistemologically, this research adopts an interpretivist approach, in which the meanings individuals attribute to their lived experiences are considered central to understanding social life (Crotty, 1998). However, it also draws from critical theory, recognising that the processes through which knowledge and meaning are produced are entangled with power relations and ideological structures. This stance is especially relevant when exploring suffering and disability in digital spaces, where sociocultural hierarchies and technological affordances mediate representations of illness. In this context, knowledge is understood as both situated and political, emerging within networks of discourse and practice that simultaneously constrain and enable expression.

This philosophical positioning supports the study's inductive and iterative methodology, in which theory is generated through engagement with participants' narratives and observations of practice over time. In this regard, the research aligns with constructivist grounded theory (Charmaz, 2014), as it recognises that data and analysis are co-constructed through the interpretive relationship between researcher and participant (Alvesson and Sköldberg, 2018). However, this study is distinct in that it employs *habitus* as both a theoretical framework and a methodological tool, allowing knowledge to be understood as embodied, situated, and relational. This critical–interpretivist positioning therefore justifies the use of netnographic observation, participant journaling, interviews, and the application of Critical Discourse Analysis (CDA). Collectively, these methods facilitate an exploration of how suffering, identity, and agency are expressed and negotiated within digital landscapes, while remaining attentive to the broader social structures and cultural practices that shape them.

Habitus as a method of enquiry

Where *habitus* was discussed in the literature review as a theory, there is also justification for using *habitus* as a methodological tool. Indeed, it could be regarded that 'the use of Bourdieusian concepts as theory separated from method is something of a concern, given that Bourdieu's conceptual apparatus was an attempt to reconcile practice and theory through method' (Costa et al., 2018, p.20). However, using *habitus* as a research method has faced criticism. Some critics argue that *habitus* can be challenging to define and measure objectively, leading to interpretations that may reflect a researcher's biases (Gerrans, 2005). Indeed, Bourdieu (2000) noted that 'habitus is neither necessarily adapted, nor necessarily coherent' (p. 160).

It can also be argued that *habitus*, as put forth by Bourdieu, fails to account for the influence of gender in shaping social dispositions, an important point to consider given the disproportionately high number of women who suffer from ME/CFS. McCall (1992) critiques Bourdieu's reluctance to view gender as a form of capital, arguing that Bourdieu sees gender as of minor significance to the subject and is rather preoccupied with the view that female gender status is imbued with uncontested symbolic violence rather than viewing gender in a systemic fashion (p. 843). Bourdieu later addressed this notion of gendered *habitus* and gender capital, where he examined the concept through a gendered lens. He notes that 'each of the two genders is the product of the labour of diacritical construction, both theoretical and practical, which is necessary in order to produce it as a

body socially differentiated from the opposite gender (in all the culturally pertinent respects), i.e. as a male, and therefore non-female, *habitus* or as a female and therefore non-male *habitus*' (Bourdieu, 2001, p. 23). Although this is a binary acknowledgement of gender based on othering, it nevertheless introduces the importance of gender to the framework. This study finds McCall's (1992) description of *habitus* as 'a powerfully elaborate conceptual framework for understanding the role of gender in the social relations of modern capitalist society' (p. 836) persuasive and relevant.

Additionally, some argue that *habitus* may overlook individual agency and variation within social groups, instead emphasising the role of structure in shaping behaviour, suggesting that *habitus* is a reductive and objective framing of human behaviour (Schatzki, 1987; Jenkins, 1992; King, 2000; Archer, 2010). When evaluating *habitus* as a practical theory, King (2000) argues that it is a poor measure of social reproduction, as not only may a *habitus* not match its field, but the concept reduces the importance of agency and reduces the complexities of social reproduction by prioritising a structuralist framework. He suggests that *habitus '*explains social reproduction by casting a shroud of deadening objectivism over living interactions between virtuosic individuals. It's account of social reproduction is a parody of the actual process by which social relations are sustained' (p.429). King's argument is itself reductive, as it ignores the longitudinal and multiplex nature of Bourdieu's proposition and that the theory suggests both objective forces (social structures) and subjective forces (individual agency) shape an individual's *habitus* as a collaboration rather than via domination of agency by organised power (Bourdieu, 2018). While all social scientific inquiry necessarily entails a degree of abstraction and objectivisation, this does not invalidate theoretical frameworks that explicitly account for the interplay between structure and agency.

Some degree of methodological structure and analytical organisation is necessary within any research design. Wacquant (2013) advocates for using *habitus* as both an empirical object and as a method of enquiry and suggests three criteria required to optimise *habitus* as a methodological tool. He states,

> The first, *synchronic and inductive*, is to trace out connections between patterns of preferences, expressions, and social strategies within and across realms of activity so as to infer their shared matrix. […] The second, *diachronic and deductive*, is to map out the social trajectories of agents so as to reconstitute the sequencing and sedimentation of layers of dispositions across time, […] The third, *experimental*, […]

> it consists of studying the dedicated institutions and focused pedagogical programs that forge a specific habitus by submitting to them in the first person (p. 40).

To satisfy these three criteria, this research adopts a method that enables the researcher to trace patterned connections within digital fields, to examine dispositions over time through longitudinal engagement, and to immerse oneself within the field to observe both community practice and the institutional actors that shape it (e.g., charities, government bodies, healthcare systems, media, and platforms). This approach allows dispositions and agreements to be identified within the fields in which they originate or are transformed.

Fieldwork approach and setting

Digital landscapes are now integral to everyday social practice, shaping how people communicate, share, and construct meaning. They encompass networked spaces such as social media platforms, blogs, forums, and virtual communities, environments that, as Goggin and Newell (2003) note, are 'digital, converging, and networked' (p. 4). Understanding these environments is central to this research, which investigates how communication practices within them mediate and make visible the experiences of people with ME/CFS.

Language in digital spaces carries complex cultural meanings. Each online community develops its own lexicon, a 'dictionary of practice' that reflects shared experiences and norms. As Hickman (2023) explains, disability-related communication often takes the form of 'crip authorship' (p. 334), an evolving linguistic archive that captures otherwise marginalised ways of speaking about the body and illness. For researchers, understanding this coded language is vital to ensure accurate interpretation and to avoid imposing external assumptions on community meaning-making.

Hine (2000) describes the internet as both a culture and a cultural artefact, arguing that online spaces merit ethnographic exploration in their own right. This approach, often termed virtual ethnography, enables the study of social interaction, meaning-making, and identity construction in digital contexts. Rogers (2023, p. 94) highlights its suitability for researching ME/CFS communities, noting that social media, patient-led encyclopaedias, and remote forums constitute much of their daily life. Because individuals with ME/CFS often experience mobility restrictions and fluctuating health, their participation in online spaces provides a crucial link to sociality and knowledge exchange. Immersion within

these digital environments, therefore, offers researchers a practical and ethical means of accessing authentic experiences of illness and community life.

While virtual ethnography emphasises immersion, this study adopted a netnographic approach to provide greater structure and transparency. Kozinets (2019) defines netnography as the systematic study of online cultural experience through investigation, interaction, and immersion (p. 14). The method provides a framework for documenting digital participation while maintaining analytical rigour. It mitigates potential bias by requiring researchers to predefine sampling, observation, and data recording procedures, which is crucial given the researcher's insider status as a person with ME/CFS. . Netnography, therefore, provided a rigorous means of observing community interactions, shared norms, and emergent discourses across digital platforms while maintaining reflexive awareness of how the researcher's positionality shaped access, interpretation, and engagement with the field.

Previous health-related netnographies demonstrate its value in uncovering lived experiences often absent from clinical research. Studies of diabetes (Tenderich et al., 2019), epilepsy (Fazekas et al., 2021), and health education (Roland et al., 2017) show that social media facilitates meaningful exchange, peer support, and collective problem-solving. For people with ME/CFS, an often invisible and under-researched condition, online interactions similarly provide spaces for validation and the co-construction of practical knowledge. These precedents reinforce the suitability of netnography for this study's aims.

Facebook was selected as the primary platform for this research due to its extensive use among ME/CFS communities and its affordances for multimodal communication. As Stetten et al. (2019) found, Facebook groups for disabled users facilitate peer support, raise awareness, and provide safe spaces for responding to news and policy issues. The platform's integration of text, images, and hyperlinks also enables the circulation of external resources, making it well-suited to observing the multimodal features of the discourse analysed in this study. Dalsgaard (2016) similarly notes that Facebook 'merges home and away' (p. 110), a feature particularly relevant for homebound individuals with ME/CFS whose social lives often occur largely online.

In summary, the combination of virtual ethnographic sensibilities and structured netnographic methods enabled both immersion and analytic rigour. This section has outlined the platform setting, the rationale for selecting Facebook as the primary site of observation, and the relevance of digital community language to interpreting ME/CFS discourse. The next section moves from setting to method, detailing the study's timescale, sampling and recruitment, and the specific procedures used for netnography, journals, and interviews.

Interviews and journals

Netnography and virtual ethnography, like all qualitative methods, warrant certain considerations. In a study investigating public health education in online environments, Wallace et al. (2018) employed ethnography to encourage participation in online communities. Their experience of the process highlighted the phenomenon that digital landscapes are often populated with communication from a few actors rather than by large inter-community dialogues. These leave netnographic and virtual-ethnographic research vulnerable to producing generalisations that may be meaningful to the loudest members of communities rather than findings relevant to a wider community. Where this provided justification for moving away from a passive approach, they also found that it added complications to the rigour of the process. They argued that

> Despite all manner of creative elicitation strategies, there is laborious "slog" involved in garnering participant activity in online communities. This "netnographic slog" often precedes the emergence of vibrant communities and needs to be hands-on, consistent, and constant. If netnographers can maintain this momentum, even when members themselves are (still) not actively engaging, they can benefit from the hard work invested "behind the scenes" (p. 1).

In addition to the rigour required to conduct netnographic research, it should be noted that numerous studies suggest that people present themselves differently online than in person, adding further complexity to the process. Online, individuals have the freedom to be selective and are not constrained by physical appearance, race, gender, or socioeconomic status (Kim et al., 2011; Hu et al., 2015). Some people engage in deceptive practices such as false representation, which has been documented in several studies (Kim and Bake, 2014; Fox and Rooney, 2015; Bareket-Bojmel et al., 2016).

To bring further levels of authenticity to findings, it is therefore judicious to consider

additional modes of interaction with the population being studied. Lawless et al (2020) employed such an approach when investigating how older adult communities use digital landscapes to communicate their healthcare needs. Their research used qualitative netnography in conjunction with a second phase of workshops with older adults and their carers. Their mixed-methods approach enabled them to identify themes through netnography and to bring these themes into workshops, yielding further insights through direct discussions with participants. They found this method to be particularly successful in unveiling credible, relevant and meaningful understandings relating to the field of digital sociology and intend to use the same methodology for future stages of their long-term project.

This research adopts a protocol that combines netnographic investigation and interviews as complementary techniques. Where much social science research relies on interviews alone to capture data, this approach may introduce a risk of reflexivity, which can obscure or alter thoughts or understandings formed at the time of an event due to a time-lapse between the event and its recollection. When discussing the difficulties of relying on recollection in social research, Caetano (2014) stresses that 'Each person’s discourse is filtered by memory, experience, social circumstances and emotional states, and these constrain access to what they actually thought at a given moment in their lives' (p. 230). However, this research explores *habitus*, which refers to dispositions formed over time, and uses interviews as part of a longitudinal methodological toolkit rather than as the sole method employed. To this end, this research builds on the body of qualitative work that investigates *habitus* through interviews (Davies, 2015; Costa and Murphy, 2015; Costa et al., 2019).

Method

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Timescale

A longitudinal approach to data sourcing was adopted. Prior to engaging with participants, the researcher spent six months conducting a netnographic study. Subsequently, participants were given a three-month period to engage in journaling. Following this, interviews were conducted. After 17 months, the netnographic process was repeated for one month. Internet cultures can be particularly transient or fast-changing. The characteristics of viral activity or, indeed, activities of health activism, as described in the previous chapter, are by their nature timely or momentous. Therefore, associations or agreements made in orbit to web-based events do not necessarily endure. Taking this approach to re-engage in the netnographic process after a period of time allowed the researcher to evaluate whether the findings were enduring, thereby strengthening their integrity. This process afforded the researcher broader access to participants' experiences and the potential to understand how community agreements evolved and endured. The data collection process spanned 18 months in total.

Participant sampling

As this research focuses on engagements in cyberspace, it was deemed most appropriate that recruitment be conducted accordingly. The study's participants were recruited through online advertising posters that were shared on social media platforms. To ensure credibility, reputable gatekeepers such as charities that support ME/CFS shared the posters on their social media channels. Gatekeepers were given an information sheet regarding the project. Interested parties were encouraged to email me for more information and to confirm their eligibility based on the following criteria:

1. Received an official diagnosis of ME/CFS from a medical professional.
2. Aged 18 or over.
3. Use social media to source information about ME/CFS.
4. Aware of and engage with certain social media channels such as ME/CFS awareness charities and forums.

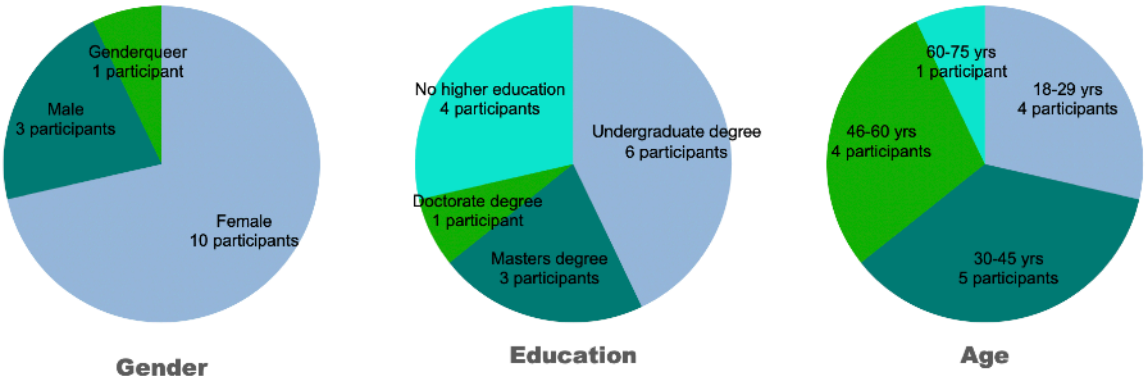
Participants who met the criteria received a participant information sheet and a consent form via email. I followed up with them via email to ensure they were comfortable with the research format and willing to participate in a journal activity and a follow-up interview.

After confirmation, they received their journal activity. All posters and information sheets were approved during the UREC's ethical review process.

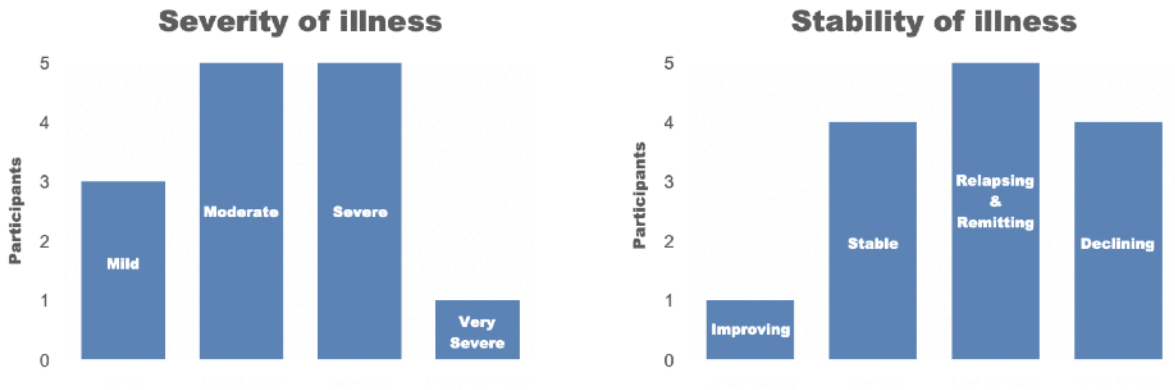
Details of recruited participants			
Pseudonym	**Age Bracket**	**Ethnicity**	**Gender**
Participant A	30-45	White British	Female
Participant B	18-29	White British	Genderqueer
Participant C	61-75	White British	Male
Participant D	30-45	White British	Male
Participant E	30-45	White British	Female
Participant F	18-29	White British	Male
Participant G	46-60	White Irish	Female
Participant H	30-45	White British	Female
Participant I	46-60	Black British	Female
Participant J	18-29	White British	Female
Participant K	46-60	White British	Female
Participant L	18-29	White British	Female
Participant M	46-60	White British	Female
Participant N	30-45	White British	Female

Ten of the 14 participants identified as female, reflecting the prevalence of ME/CFS in the broader population. There was a balanced distribution of age groups from 18 to 60, with only one participant older than 60. Ten of the 14 participants held at least one university degree, a proportion higher than that in the general population (Clark, 2023). The participant sample was also predominantly white, with only one participant identifying as being from a minoritised ethnic background. This demographic composition reflects a broader issue frequently identified within ME/CFS research and advocacy spaces, where experiences and narratives represented within patient communities, support organisations, and research participation are often disproportionately white. While this study did not adopt an explicitly intersectional analytical framework, it is important to acknowledge that experiences of illness, diagnosis, digital participation, credibility, and healthcare access are shaped by intersections of race, ethnicity, gender, class, and disability. Accordingly, the findings presented in this thesis should not be assumed to represent the experiences of all

people living with ME/CFS equally, particularly those from racialised or otherwise structurally marginalised communities whose experiences may differ in important ways.



The participant sample also self-reported a broad range of illness severity and stability.



Although this sample demonstrated diversity in gender, age, and illness severity, it was equally important to ensure that the sample size was appropriate for the study's aims and design. While the overall sample size of 14 participants may appear modest, it was deemed suitable and sufficient for the objectives of this qualitative, longitudinal investigation. In qualitative research, adequacy is determined not by statistical representation but by the information power of the sample, that is, how rich, relevant, and capable of answering the research questions the collected data are (Malterud et al., 2016). According to this framework, information power increases when the study's aim is narrow, when participants hold specific experiences relevant to the research focus, and when the quality of dialogue is high.

Since this project engaged participants with lived experience of ME/CFS in various in-depth ways, including journaling and interviews, the design prioritised depth over breadth. Each participant provided detailed, longitudinal insights that captured the evolving relationship between digital environments, illness experience, and social identity. This approach supports analytical generalisation rather than statistical generalisation, allowing the findings to reveal conceptual and thematic patterns rather than population-level trends. Accordingly, the sample was considered to have strong information power and to be methodologically suitable for achieving the study's aims. Taken together, these considerations demonstrate that the participant group was both adequate and well-suited to the study’s qualitative focus, providing a strong foundation for subsequent data collection and analysis.

Data Collection

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Data was sourced in three different ways, via (1) initial netnographic research, (2) from journals completed by people with ME/CFS, and (3) through direct online video interviews with people with ME/CFS.

1. Netnographic data

Data collected during the netnographic process involved systematically selecting two–four "discussion points" per week over six months, using a mixed logic: (i) a time-based sweep to capture what was salient in the community that week, and (ii) theory-guided selection where posts aligned with the study's sensitising concepts (e.g., legitimacy work, evidence disputes, pacing/treatment talk, welfare/healthcare encounters, or platform visibility dynamics). These discussion points were varied and included multimedia. This dataset included memes and videos; questions from community chats; information posts; discussions about the latest science and medicines relevant to ME/CFS; news media related to ME/CFS; and conversations about such content.

These discussion points were collected from a mix of public Facebook pages/groups and join-to-access (semi-private) groups where membership was required to view content; in both contexts, I treated posts as ethically sensitive due to the health-related nature of disclosure. These often included or linked to content from other digital portals and social networks. Particularly Instagram, X, TikTok, blogs, YouTube, charity websites, news media outlets, government websites, and peer-reviewed journals. These Facebook forums included: two UK ME/CFS charities, two ME/CFS UK community friendship groups run and managed by people with ME/CFS, and three ME/CFS help groups also run by people with ME/CFS. These help groups included forums designed to help people with ME/CFS understand and navigate the UK benefits system, the social care system, treatment programs, and new and emerging research into ME/CFS. I spent six to eight hours per week navigating these spaces, and discussion points were collected when deemed pertinent to the thematics of this research project.

Netnographic data corpus

- **Platform and settings:** Public Facebook pages/groups and join-to-access (semi-private) Facebook groups related to ME/CFS (UK-based charities and peer-run community/help groups), with linked material circulating from but not limited to: Instagram,

X, TikTok, blogs, YouTube, charity websites, news outlets, government pages, and peer-reviewed articles.

- **Observation period:** June 2023 to Nov 2023 (initial phase), plus a follow-up observation phase in Nov 2024.
- **Researcher stance:** Observational ("lurking") rather than participatory posting.
- **Sampling logic:** Each day, I selected 2–4 discussion points using a mixed logic: (i) a time-based sweep to capture what was salient in the community that week, and (ii) theory-guided selection where posts clearly aligned with the study's sensitising concepts (e.g., legitimacy work, evidence disputes, pacing/treatment talk, welfare/healthcare encounters, or platform visibility dynamics).
- **Unit of analysis:** A "discussion point" was defined as [e.g., a single post plus its comment thread / a thread + linked artefact (meme/video/article) + comments], treated as one analytic unit.
- **Approximate corpus size:** 572 discussion points captured across the initial six-month phase, plus 60 captured during the follow-up month (total 632).
- **Purpose in the design:** Netnography was used to (i) map the discursive environment, (ii) generate sensitising themes that informed the journals/interviews, and (iii) support cross-dataset comparison during analysis.

2. Participant data from journals

Fourteen people with ME/CFS completed an in-depth journal over a three-month period. The journal was divided into four sections.

Section A: Relationship with ME/CFS

Questions explored participants' diagnosis, the support they receive, and the impact of ME/CFS on their lives.

Section B: Social representation of ME/CFS

This section examined perceptions of ME/CFS and suffering, and how the illness is understood within participants' immediate and wider social networks.

Section C: Legacy media coverage

Participants reflected on how ME/CFS has been reported in print, radio and television, providing examples and discussing their responses to this coverage.

Section D: Digital media and online support

The longest section focused on participants' use of digital media to access information, advice and community. It also explored how they manage and interpret suffering online, authenticate information, and engage with social media.

The complete list of journal questions is provided in; Appendix: Participant Journal.

3. Participant data from interviews

Twelve of the 14 participants who completed their online journals participated in online video interviews. Two of the participants were omitted from this process as they have severe/very-severe ME/CFS. This severity meant that they were unable to communicate verbally due to poor health. The interviews were conducted using Microsoft Teams and were recorded and transcribed immediately. Interviews were semi-structured and guided by a flexible topic guide derived from the netnography and participants' journal entries. To minimise cognitive and physical exertion, interviews were typically limited to 20–30 minutes per session, with shorter sessions (approximately 10 minutes) used when participants experienced severe fatigue or a heightened risk of post-exertional malaise. Where needed, interviews were split across multiple sessions on different days. Participants were also invited to submit follow-up reflections via email after the interview to reduce real-time processing demands and to enhance the accuracy of their recall. Audio recordings were transcribed and checked against the originals for accuracy before analysis, and the transcripts were anonymised and assigned pseudonyms.

During the interviews, participants were asked to expand on some of the data entry in their journals. They were asked to discuss how they navigate internet spaces, particularly those they engage with while performing, living, and observing suffering. During the interview process, discussions circulated topics such as experiences of the mediation of suffering in digital environments, articulations of exchanges of capital, effective and ineffective information sourcing strategies that they would partake in, negotiating their health protocols based on experiences in digital landscapes, information sourcing; sharing their lived experiences of ME/CFS; experiences of agency and power within digital landscapes as well as the dispositions and agreements made in connection with such experiences.

Interviews offered opportunities to expand, clarify, and reflect through dialogue. Wallace et al. (2018) warn that digital communities are often dominated by a small number of vocal

actors, which can skew observational research. Interviews helped counter this by highlighting a wider range of participant voices. They also strengthened the reflexive aspect of the project. Flick (2018) emphasises that qualitative triangulation, combining methods such as observation, journalling, and interviewing, improves both the richness and credibility of findings. By integrating these three approaches, the study was able to capture not only what was said in digital landscapes but also how individuals interpreted these interactions in their own lives

Safeguarding

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Participant safety

As ME/CFS is a fluctuating illness with varied symptoms and various limitations, people with ME/CFS cannot necessarily manage a simple activity such as a prolonged phone call with reliability, consistency or safety. Common symptoms of ME/CFS include chronic fatigue, pain, problems with concentration, speech and language problems (including word finding), dizziness and sensitivity to light and sound. As such, they may also experience harm from overexertion during participation due to post-exertional malaise (PEM). With this in mind, any framework for working with participants from this population must be sufficiently flexible to accommodate the needs of each individual participant. Before participants engaged with the project, a working practice was negotiated with each participant, emphasising the importance of staggered involvement according to their capabilities.

It was emphasised that participants shouldn't be involved in interviews lasting more than 20-30 minutes per session. For some participants with severe ME/CFS, multiple 10-minute interviews were conducted to prevent over-exertion. This working practice also included flexibility regarding the interview procedure. For example, some participants were interviewed once, whereas others were interviewed multiple times, necessitating the spread of the interviewing process across days or weeks.

As memory and exhaustion are profound issues for this population, to minimise overexertion during the interview process, participants were invited to send their follow-up thoughts via email after the interviews. This allowed them to contribute more deeply as they could share their thoughts in a manner that suited their fluctuating ability. Also, as participants expressed a keenness to contribute as thoroughly as possible, I was strict about protocols that could exacerbate illness symptoms, such as in-depth interviewing.

During the data capture period, participants were also encouraged to complete journals in short bursts over three months. While beneficial for the longitudinal nature of the study, this protocol also served as a safeguard to protect participants from overexertion. Furthermore, I completed LJMU's ethics training and this protocol was favourably approved by the University Research Ethics Committee (EURC).

Beyond procedural safeguarding, the study approached care as an ongoing relational responsibility within the research encounter itself. Because participants were living with fluctuating and energy-limiting illness, ethical practice involved remaining attentive to signs of fatigue, cognitive strain, emotional overwhelm, and post-exertional malaise throughout all stages of engagement. This meant prioritising participants' wellbeing over data generation where necessary, including shortening interviews, pausing discussions, extending timelines, or accepting partial participation without pressure for completion. Within this framework, flexibility was understood not as a compromise to methodological rigour, but as an ethically responsive practice aligned with crip methodology and interpretivist principles of participant-centred research.

Anonymity

All participants are referred to in this thesis by pseudonyms. Any references to the participant's culture that could be used to identify them, such as their place of residence, work, schools, heritage, culture, or age, were anonymised or omitted. References to their personal networks, such as friends, family, work colleagues or indeed internet and social media friends/contacts, were all pseudonymised, anonymised or omitted if it is felt that anonymisation wouldn't be possible.

In addition to real-world identifiers, all online identity details, such as names and avatars, were also omitted. Although every effort was made to anonymise participants' data and the data of their extended networks, it cannot be ignored that this research is preoccupied with communication occurring in digital spaces. Given the nature of this research, the participant sample and the digital landscapes they inhabit collectively constitute a social grouping that is particularly large and varied. Whilst this in itself does not expose them individually, the utmost care was given to omitting incidental details about both participants and their discussed networks/communities. This was discussed with each participant, and they were given the opportunity to influence this decision-making process. In particular, where relevant, it was discussed which incidental details were acceptable or unacceptable to include; these included but were not limited to age, sex, location, political affiliation, family status, work, heritage, and ethnicity.

All data collected through netnographic research was also anonymised by removing names and locations. To further protect anonymity, the names of the Facebook groups and forums from which the data were collected were also omitted.

Netnographic ethics and expectations of privacy

Although the netnographic component drew primarily on public Facebook pages and groups, it also included join-to-access (semi-private) groups where “joining” was required to view content. I treated both contexts as ethically sensitive because they involve health disclosure and potentially identifiable narratives.

Following guidance within digital ethnography and internet research ethics, I worked on the assumption that public accessibility does not automatically equate to participant consent for academic reuse, particularly in contexts of illness and vulnerability. I therefore adopted a harm-minimisation approach.

* I did not reproduce usernames, profile images, locations, or group/page names.
* I removed incidental identifiers from posts and comment threads.
* I avoided including verbatim quotations that could be searchable and traceable back to an individual account.

Where the thesis includes memes or other visual artefacts, these were handled as potentially identifiable cultural objects. To reduce traceability while preserving analytic value, I prioritised (i) memes that were already widely circulating across multiple platforms, (ii) partial description of visual content where reproduction was not essential, and (iii) where reproduction was necessary for multimodal analysis, the use of de-identification steps (e.g., removing usernames, timestamps, watermarks, or group-specific markers; cropping; and obscuring any personal identifiers). In all cases, the aim was to preserve the discursive and visual features relevant to Critical Discourse Analysis while minimising the risk that an individual user or specific community space could be re-identified. Where an artefact originated in a join-to-access group and was not evidently widely circulating elsewhere, it was reported through analytic description rather than reproduced, to reduce contextual re-identification risk. I stored all extracted material securely, consistent with ethical approval and safeguarding commitments.

Data Analysis

Data included both text and visual data, such as memes or photographs. As this research project focuses on the social practice of communication and examines data in the form of verbal and text/image-based discourse, critical discourse analysis (CDA) was employed to explore and discus the data. Fairclough (2001) argues that CDA is the most appropriate action if we wish to illuminate 'the problems which people are confronted with by particular forms of social life, and to contributing resources which people may be able to draw upon in tackling and overcoming those problems' (p. 125). During the initial analysis, themes were consolidated regarding their impact on living with ME/CFS, the relationship between people with ME/CFS and their immediate communities, wider communities and organisational power, and the relationship between people with ME/CFS and treatment. Treatment is a term used here both in the medical sense and in the social application of the word. This method has been chosen as CDA, 'focuses on social problems, and especially on the role of discourse in the production and reproduction of power abuse or domination' (van Dijk, 2001, p. 96). As CDA is fundamentally concerned with analysing structural relationships of dominance, discrimination, power and control as manifested in language (Wodak, 2001; 2009), it provides a suitable means to interrogate how cyberspace is used to perform, witness, share, live, inform, aid, treat, politicise and govern suffering. Van Dijk (1997), when outlining a framework through which to conduct CDA, argues that the key to understanding power structures is to understand how ideologies are expressed. As such, an important part of this data analysis included seeking out and contextualising these coded expressions, such as irony, vagueness, rhetoric, hyperbole, polarisation, presumption, dog-whistling, euphemism and disclaimers.

Critical Discourse Analysis (CDA) was carried out using Fairclough’s (1995) three-dimensional model, which conceptualises discourse as operating simultaneously at the levels of text, discursive practice, and social practice. This approach enabled the analysis to move beyond superficial description towards understanding how meanings are constructed, circulated, and embedded within broader power relations. At the textual level, attention was given to vocabulary, grammar, metaphor, and modality, considering how linguistic and visual choices served to represent or frame experiences of illness and suffering. At the level of discursive practice, the analysis examined how these texts were produced, distributed, and consumed within digital environments, including how participants shared, reposted, and recontextualised material from other platforms. Finally,

at the level of social practice, the analysis situated these discourses within wider socio-political structures and ideologies, particularly those shaping perceptions of disability, wellness, and productivity in late-modern digital culture. This multi-layered process was iterative and interpretive. Each stage of analysis informed the next, allowing evolving insights to be revisited as new data were incorporated. Following Titscher et al. (2000), this process combined micro-linguistic analysis of textual features with macro-sociological interpretation, ensuring that meaning was understood both within and beyond the immediate communicative event. In this way, CDA served as a bridge between the lived and linguistic, linking participants' everyday expressions of suffering with the social frameworks that govern their recognition and legitimacy.

To illustrate this process, one example can be taken from analysing Facebook discussions concerning pacing and energy management. Posts and comments frequently employed metaphors of combat, such as 'fighting fatigue' or 'battling the crash.' At the textual level, these metaphors were identified as lexical indicators of struggle and resilience. In terms of discursive practice, their repeated use across many users' posts showed a shared communication norm within ME/CFS communities, emphasising the moral importance of endurance. At the social practice level, these discourses were viewed in a broader neoliberal context that values productivity and self-management. This suggests that the language of combat can both empower and limit individuals by linking illness management with stories of personal responsibility (see also Gee, 2014). This layered approach ensured that the CDA process was transparent, replicable, and aligned with the study's Bourdieusian framework. By viewing discourse both as a form of symbolic capital and as a mechanism of power, the analysis showed how individuals with ME/CFS navigate, reproduce, and sometimes challenge dominant discourses surrounding illness, legitimacy, and care within digital environments.

To support systematic organisation and analysis, the following stage of data handling involved the use of *Numbers* software to document, code, and cross-reference textual and visual materials. *Numbers* software was used to collate and code all the data in one document to enable ease of cross-referencing. This data was coded for thematics such as experiences or performances of suffering, articulations of exchanges of capital, effective and ineffective information sourcing or sharing, experiences or articulations of agency and power, as well as the dispositions and agreements made in connection with all such experiences. Using this software enforced research discipline as it helped mitigate

preconception bias and allowed categories and subcategories of thematics to evolve during the data analysis process. After this coding process, a secondary coding process was deployed. This process further labelled all of the data into three core discussion categories, which are outlined below.

1. Treatment: This category included all data related to using digital landscapes to develop treatment protocols. This included discussions about repurposing FDA-approved medications for other conditions and trialling them in patients with ME/CFS; hacking existing technologies to manage and/or monitor ME/CFS symptoms; and participating in ME/CFS research trials, particularly by engineering ways for housebound participants to engage remotely. It also covered discussions on well-being practices, including traditional Western medicine, alternative medicine, and lifestyle approaches. Additionally, it included data focused on narratives about harm.

2. Evidence of a political-biosocial *habitus*: This category includes data on how people with ME/CFS use digital platforms to discuss and develop language about the illness. It contains examples of conversations comparing medical and non-medical terminology, as well as efforts to create or adapt language specific to ME/CFS. The data also include discussions aimed at shaping public and media narratives, alongside exchanges about trust, truth, and the assessment of information within digital spaces. Finally, the category records examples of collective knowledge-building, such as the creation of community databases, archives, and visual materials used to represent and organise shared understandings of the condition.

3. ME/CFS and Society. This category includes data on how people with ME/CFS interact with broader social structures and power fields. It contains examples of discussions about experiences with government agencies, welfare and benefit systems, and healthcare institutions. The data also include narratives exploring disability pride and disability shame, as well as exchanges about governance frameworks that define or regulate sickness. Finally, the category records conversations about the social model of disability and how community members engage with, challenge, or reinterpret it in relation to their lived experiences.

These approaches collectively enabled me to identify key themes across the data and to interrogate the social meanings embedded within the participants' discourse. To ensure

that these analytic processes were not only interpretively rich but also methodologically robust, the following section outlines the measures taken to establish the trustworthiness and rigour of this study.

Integration of Methods and Analytical Framework

The design of this study was structured to allow each method to inform and deepen the others while maintaining a clear analytic sequence. Netnographic observation provided the contextual foundation by mapping the discursive environment in which ME/CFS communities communicate. These observations generated preliminary thematic categories that guided the focus of the participant journals and interviews, ensuring that subsequent data collection was responsive to the lived discourses already emerging in digital spaces.

The integration of these datasets was achieved through the application of Critical Discourse Analysis (CDA) as the unifying analytic lens. CDA enabled the interrogation of how representations of illness, legitimacy, and suffering operated across text, image, and interaction. This approach was particularly suited to digital landscapes where communication is multimodal, combining written text, emojis, images, hyperlinks, and memes. Accordingly, the analysis incorporated principles from Machin and Mayr's (2012) framework for multimodal CDA and from Kress and van Leeuwen's (2020) concept of 'visual grammar', which together informed how visual and linguistic elements were interpreted as co-constitutive of meaning.

By employing CDA across all three datasets, the research examined how discourse both reflects and constitutes *habitus*. Operationally, *habitus* was made visible through the identification of discursive regularities across datasets. Recurrent lexical choices, metaphors, interactional norms, and visual motifs that signalled durable orientations within the ME/CFS community. These recurrent features were coded as indicators of embodied dispositions, allowing CDA to function as a methodological bridge between textual representation and social practice. In this way, the analysis treated discourse as the observable manifestation of *habitus* in action. Linguistic markers of endurance, metaphors of struggle, and the visual iconography of chronic illness were interpreted as discursive expressions of embodied suffering. In this way, discourse was treated not simply as representation but as social practice, through which participants enact, negotiate, and contest their social identities. The analytic sequence, therefore, moved from field observation (netnography) to narrative articulation (journals and interviews) and finally to

discursive interpretation (CDA), maintaining a coherent methodological thread from data generation to theoretical analysis. Together, these stages constitute an iterative design that aligns data generation with theory-building through the lens of *habitus*.

Trustworthiness and Rigour

In qualitative research, validity and reliability are often reframed as trustworthiness, which encompasses credibility, dependability, confirmability, and transferability (Lincoln and Guba, 1985). Establishing trustworthiness was central to the design of this study and to the interpretation of its findings. Credibility was established through triangulation of multiple data sources: netnographic observations, participant journals, and semi-structured interviews. Using several complementary methods enabled cross-validation of findings, ensuring interpretations were based on consistent patterns observed in various contexts.

Extended engagement within digital landscapes over the 18-month research period further reinforced credibility by providing a sustained and authentic understanding of social practices, cultural references, and discursive exchanges in these online spaces.

Dependability was assured through a clear, traceable audit trail. Coding documentation was systematically organised using Numbers software, allowing data to be cross-referenced and revisited throughout the analysis. This structured approach ensured that decisions could be tracked, reviewed, and verified, demonstrating consistency and transparency in data management and interpretation over time. Confirmability was achieved via ongoing reflexive practice.

I kept a reflexive log during data collection and analysis to document decisions, assumptions, and personal reflections. This supported ongoing reflexive awareness regarding how my own lived experience, assumptions, and emotional proximity to the topic might shape interpretation. Maintaining a reflexive log helped ensure that analytic decisions remained transparent, accountable, and grounded in participants' accounts while recognising the interpretive nature of qualitative research. The use of double-coding enhanced confirmability by encouraging critical re-examination of coding decisions and interpretive assumptions across different stages of analysis. Transferability was supported through detailed contextual information about participants, settings, and digital environments. Although this study does not aim for statistical generalisation, such rich

descriptions enable readers to assess whether the findings could be relevant to other contexts, populations, or investigations of digital suffering and chronic illness.

Collectively, these measures establish the methodological integrity of the study and demonstrate that it meets accepted standards of qualitative rigour. The study's design, reflexive transparency, and systematic documentation provide assurance that the findings are both credible and trustworthy. While these strategies reinforce the robustness of the research, the following section considers the practical and theoretical limitations that inevitably arise when conducting longitudinal qualitative inquiry with chronically ill populations.

Power Relations, researcher standpoint and rapport

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Researcher Positionality and Disclosure

It is pertinent to acknowledge that since 2009, I have lived with a diagnosis of ME/CFS, a fact disclosed to all participants involved in the study. Within an interpretivist and ethnographic framework, this positionality was not treated as a source of contamination to be removed from the research process, but as part of the relational context through which knowledge was co-produced. Disclosure fostered rapport and trust between participants and me, while also enhancing my familiarity with the terminologies, practices, and social dynamics circulating within ME/CFS digital environments. At the same time, this shared positionality required ongoing reflexive accountability regarding how my own experiences, assumptions, and emotional investments might shape interpretation. Rather than attempting to eliminate subjectivity, the methodological aim was to remain critically attentive to how meaning was negotiated within the research encounter. Accordingly, several reflexive practices were embedded throughout the study design. Interviews were structured around issues participants had already raised within their journals, reducing the likelihood that discussions would be overly directed by my own assumptions or priorities. Reflexive logging, iterative coding, and revisiting data across stages of analysis enabled interpretations to remain grounded in participants' accounts while acknowledging the interpretive role of the researcher. These methodological decisions align with broader ethnographic debates concerning researcher visibility, situated knowledge, and the co-construction of meaning within qualitative inquiry..

The Ethnographic Self and Lived Experience

As a component of ethnographic study, the 'researcher self' or 'ethnographic self' (Coffey, 1999) has become increasingly prevalent in the social sciences. Techniques such as confessionals and personal reflection, whilst allowing researchers to place 'the biographical and the narrated self at the heart of the analysis can be viewed as a mechanism for establishing authenticity' (Coffey, 1999, p. 4). Although this research does not employ autobiographical techniques at its core, the researcher's lived experience as a person with ME/CFS brings a unique dimension. As such, identifying the researcher within the research facilitates the representation of more voices with lived experiences of ME/CFS, a core objective of the study. It also affords an empathetic approach to this community, which, in turn, has influenced the longitudinal approach adopted.

Where this methodology aims to create a bespoke practice that caters to the needs of those taking part in the study, this was also extended to me. While this could be viewed as a limitation, as it invites a variety of data-sourcing methods, it is also part of the validity of the methodology, as it allows participants the time they need to contribute and makes available the multiplex of communication technologies through which they may choose to communicate. Because the use of communication technologies is central to this investigation, this process was practical and relevant. These considerations of positionality and methodological design became especially visible within the research encounters themselves, particularly in how participants evaluated both the researcher and the research.

Negotiating Trust and Researcher Legitimacy

In the following chapters of this thesis, I discuss how this population organises peer-reviewed information, creates databases endorsed by community influencers, and evaluates whom and how to trust. Therefore, it is also pertinent to examine some of the interactions between me, as the researcher for this study and the participants as they evaluated both my validity and the validity of this research.

An interesting dynamic to note is the manner in which trust was declared and negotiated between me and those interviewed. At the start of each interview, I delivered a safeguarding brief on resting, taking breaks, and limiting interview duration to manage fatigue effectively. However, at this stage, I encountered further questions from six participants who asked for repetitions of information already provided, as well as additional inquiries, such as 'Is this project funded?', 'Who funded this project?', 'I understand that you are a social scientist, but do you believe that ME is a physiological illness?' and 'Why have you decided to do this type of research when [there is a far greater need] for biomedical research?'. I was also asked probing questions to clarify and confirm my diagnosis, including 'Were you diagnosed by a doctor or a psychiatrist?', 'How long have you had ME?' and 'Is your ME mild?'.

I chose to fully disclose that I was diagnosed by both my GP and a psychiatrist 15 years ago and that, while I initially experienced several years of severe ME/CFS, I have fluctuated between mild and moderate onset for the past 6 years. This sharing process appeared to alleviate any initial scepticism they may have had, with all participants thanking me for sharing, with one clarifying, 'you know, you have to be careful because we

aren’t always represented by people who have our best interests at heart.' They also demonstrated their knowledge of the academic field, as two of the participants mentioned research being carried out by a PhD student at Manchester University who was also looking at ME/CFS and social media use, and one of them referred to a PhD student in Bristol who was currently recruiting participants with ME/CFS to take part in a journaling exercise. They indicated that they were sharing this knowledge to demonstrate that they understood and approved of the project's research focus.

Crip Methodology, Language and Rapport

Rogers (2023), who spent six years conducting a virtual ethnographic study with people with ME/CFS, discusses the challenges of 'building trust and maintaining contact' (p. 95) with this population. She said that her 'preconceived notions of gaining entree and building rapport, in particular, were strained by the online platform on which my research took place' (p. 94), and she describes a disconnect between herself as the researcher and those she was trying to speak to. She correlates this with the dismissive narratives that have long surrounded the illness, which have festered distrust of those outside of the ME/CFS community. This highlights what I would argue is the necessity of ‘crip methodology’ when researching with chronically ill or disabled populations. In this context, crip methodology functions not simply as an ethical stance but as an epistemic framework that legitimises fatigue, fluctuation, and partial participation as conditions of knowledge production rather than methodological limitations.

This is particularly salient in contexts where dominant medical and social research languages have not yet evolved to incorporate crip authorship or the experiential epistemologies of people with ME/CFS. The resulting tension between the language of “the well” and the language of “the ill” operates as a structural barrier to open dialogue, often rendering lived experience illegible within conventional research encounters. It was indeed my declaration of my own diagnosis that appeared to act as a shortcut to fostering rapport with those interviewed. This shared positionality also shaped the microdynamics of the interviews, particularly in moments when participants relied on assumed mutual understanding.

Shared Language, Reflexivity and Interview Practice

There were occasions when interviewing participants, when they would resort to shorthand and the use of community language. Occasionally, participants would say something

briefly, followed by a comment such as 'well, you know what I mean' or 'as you know!' At that point, I would ask them to expand as if I had no knowledge, explaining that I wanted to avoid presuming shared meanings or prematurely interpreting their experiences through the lens of my own. This was always well received and often created particularly insightful dialogue. Unlike Rogers' (2023) experience, this methodology arguably created greater authenticity and willingness to participate from those interviewed. Frequently comments such as, 'Well, I wouldn't admit this to most people, but at one stage, I was so desperate that I was trying things that I knew had no scientific grounding, and I'm a scientist, I have a PhD, you know, so it's embarrassing to say this, but I trust you will understand why I did it…' (Participant C). The effects of this approach were not limited to interview depth but were also evident in how participants articulated trust, reciprocity, and ongoing engagement with the research.

Trust, Reciprocity and Patient-Led Knowledge Production

In addition to evidence of honesty, there was also evidence of trust, as all the participants self-volunteered to be contacted again and expressed gratitude for taking part in the research, either at the end of the interviews or by way of post-interview contact through letters of appreciation. They expressed their thanks for the opportunity, stating that they felt seen, heard, and connected. Three of them commented that, by participating in research such as this, they feel they are actively creating knowledge for their community, despite many not being able to leave the house. At the end of the interview, Participant J said, 'Thank you so much for doing this research, it's so important […] Because we sort of rely on each other, I guess quite heavily, because we can't always rely on our doctors, which is unfortunate.' Her comments underscore the heart of the findings in this thesis, that many members of this community feel a necessity to share experiences among themselves, as the trust in wider society, whether through political ideologies, a lack of funding, a lack of interest, or a lack of understanding, has allowed this community to form as a resilient "other" burdened with the task of developing their own curative practices while managing their ill health.

Limitations

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Limits of Ethnographic Observation in Digital Contexts

The approach of this thesis expands on existing qualitative work that investigates *habitus* through interviewing (Costa and Murphy, 2015). Where witnessing participants within cyberspace prior to the interview or during the interview would have been a more ethnographic approach, this wasn't possible to action for this population due to their health restrictions. Accordingly, both asking participants to complete the journalling activity and the netnographic stage of data capture that I conducted were measures designed to enhance the authenticity of the findings.

Although I was unable to observe the participants navigating cyberspace, their journals provided rich detail on this, as participants discussed occurrences in these spaces. The netnographic data capture also allowed me to spend time in cyberspace and become familiar with the digital ME/CFS *habitus*, allowing me to keep up to date with prominent cultural exchanges, timely debates, and discussions in relevant forums.

The sample of 14 participants may be considered small, but it was deemed appropriate for this qualitative study, particularly given the detailed nature of journalling, which supported the interview process and the additional contribution of netnographic data.

A further limitation concerns the demographic composition of the participant sample, which was predominantly white. As this study did not employ a sustained intersectional framework, it could not comprehensively examine how race and ethnicity intersect with disability, chronic illness, gender, or class in shaping experiences of ME/CFS and digital mediation. This is significant because experiences of healthcare access, diagnostic legitimacy, online participation, and institutional trust may differ substantially across racialised groups. The relative absence of ethnically diverse participants, therefore, limits the extent to which the findings can speak to the full heterogeneity of ME/CFS experiences. Future research would benefit from more explicitly intersectional approaches that explore how digital suffering and illness legitimacy are mediated across differently positioned social groups.

Sample Size, Temporality, and Habitus Formation

Where this study has some longitudinal components and data capture took place over an 18-month period, it can be suggested that without enduring engagement with this population, the

findings could be attributable to fashionable notions rather than an exploration of *habitus*. As previously discussed, without the affordance of time, we cannot ascertain whether creative practice in cyberspace is fleeting or wedded to cultural understandings (Burgess et al., 2018). When discussing the importance of using a Bourdieuisian social framework when we approach media studies investigation, Lindell (2015) stresses that fields don't merely provide space for *habitus*, 'fields are generative of habitus' (p. 366), and as such, we must include this assumption in our exploration of media power and, by virtue, digital landscapes. He continues further to add, 'we understand media practice as situated in a space of social positions in which agents, with different resources (capital) and dispositions (*habitus*) compete over positions, and subsequently that such practice is part of an agent's orientations in that space. Despite the 'newness' of contemporary media practice, social context remains crucial for understanding media production' (Lindell, 2015, p. 368), and by virtue, contemporary media practice has become crucial for understanding the formation of *habitus*. With this in mind, the approach taken in this study strives to allow for time to witness and assess dispositions and understandings made in digital landscapes, while supporting the notion that whilst such agreements and dispositions can appear to form with pace, this does not make them any less culturally significant. These theoretical considerations intersect directly with the ethical realities of researching a population whose capacity for participation is inherently variable.

Ethical Flexibility and Variability of Participation

During the prior discussion regarding the ME/CFS population selection for this project, it was noted that there is a significant variation in how individuals present their illness. This variation affected the consistency of participants' engagement. Two participants could provide only text-based input due to limited verbal capacity, whereas others participated in either several shorter interviews or a single longer interview. While this flexible data capture method may not have been ideal for consistency, it allowed the project to include the entire spectrum of individuals with ME/CFS. The nature of this illness means that what might be a healthy interaction with me on one day could be harmful on another day. Therefore, mitigating harm was the top priority. Adopting a flexible approach to data capture enabled the study to include the most vulnerable individuals, who would otherwise have been excluded if we had limited our discussions to those with mild, stable onset only.

As there are no established guidelines for conducting research with this population, this study aims to establish a standard for patient-focused research in ME/CFS. To broadly

represent the ME/CFS population in social science research, there can be no one-size-fits-all approach to the research methods deployed. Furthermore, this study employs a qualitative approach, given the limited research on this population. Because the ME/CFS population has been largely excluded from social science research, this exclusion provides a valid rationale for investigating it. Rather than undermining the study's validity, these constraints necessitated methodological innovation.

From Limitation to Methodological Contribution

While this methodological design necessarily incorporated flexibility and multiplicity in its data collection processes, such plurality also represents a significant contribution to the evolving field of digital qualitative research. The approach adopted here illustrates how methodological adaptability, ethical sensitivity, and theoretical coherence can coexist when researching populations whose lived experiences challenge conventional modes of inquiry. This study, therefore, makes a methodological contribution by advancing a framework that integrates longitudinal, multimodal netnography with Critical Discourse Analysis (CDA) and Bourdieusian theory to investigate digital suffering and chronic illness. By operationalising *habitus* as both a theoretical and methodological lens, the research demonstrates how embodied dispositions can be observed, interpreted, and theorised through digital communication. The methodological design, combining netnographic observation, participant journalling, and interviews within a CDA framework, extends digital ethnography by uniting linguistic and visual analysis to explore how social identity, power, and legitimacy are negotiated online.

In addition, the study contributes to disability and health research methodology by modelling ethically responsive, accessible, and longitudinal engagement with chronically ill populations. The safeguarding strategies and adaptive participation structures developed here illustrate how inclusive research can be conducted without compromising analytical depth or rigour. Therefore, the approach could inform future digital health or disability studies. By documenting reflexive practice and integrating multimodal discourse analysis, this framework offers a replicable approach for scholars examining the intersections of health, digital culture, and lived experience. Ultimately, it reframes digital ethnography as a collaborative and critical practice capable of revealing how suffering is mediated, politicised, and reconstituted within networked environments. This study contributes an original methodological framework integrating multimodal Critical Discourse Analysis and

Bourdieusian *habitus* within an ethically adaptive, longitudinal design for researching digital suffering and chronic illness.

Chapter Overview and Outline of Findings Chapters

The chapters that follow present the empirical findings of this study, interwoven with critical discussion and theoretical interpretation. Each chapter corresponds to one of the three core thematic domains identified through the analytic process: (1) Creating healthcare protocols, which explores how people with ME/CFS use digital spaces to develop, adapt, and contest treatment and self-care practices; (2) Evidence of a political-biosocial habitus, which examines how communicative practices in digital landscapes construct shared dispositions, epistemic resources, and collective identity; and (3) ME/CFS and society, which situates these digital practices within broader fields of power, policy, and representation. Together, these chapters demonstrate how sufferers engage in the mediated production of knowledge, care, and legitimacy, and how these processes illuminate the pharmacological nature of digital landscapes as sites of both healing and harm.

CHAPTER 4: FINDINGS AND DISCUSSION, PART 1, CREATING HEALTHCARE PROTOCOLS

Introduction

This chapter presents the first set of findings from the study, exploring how people with ME/CFS utilise cyberspace to create, test, and circulate healthcare protocols. It examines how participants draw upon collective knowledge, experiential expertise, and digital affordances to navigate a healthcare system that often marginalises or misunderstands their condition. Building on the theoretical framework established in earlier chapters, this analysis interprets these practices through the concepts of *habitus*, *suffering-capital*, and the *pharmacological* nature of technology. This chapter extends the conceptual framework established earlier by showing how *habitus*, *suffering-capital*, and the *pharmakon* converge in lived digital practice. Where previous chapters explored these constructs theoretically, here they are examined empirically through the actions, conversations, and embodied decisions of people with ME/CFS as they navigate fragmented systems of care.

As discussed in Chapter 2, digital environments function as spaces of both empowerment and vulnerability. They enable community building and knowledge exchange but can also reproduce hierarchies, misinformation, and symbolic violence. This duality is reflected in how participants negotiate authority, legitimacy, and trust in their healthcare practices. Drawing on the critical–interpretivist methodology outlined in Chapter 3, this chapter integrates netnographic observations, participant journals, and interviews to reveal how individuals collectively transform digital spaces into sites of biopolitical agency.

The discussion unfolds in four sections. The first explores supplements and alternative therapies, revealing how biomedical scarcity drives the creation of community-endorsed practices. The second examines “pacing”, heart-rate monitoring, and Vagus Nerve Stimulation, as forms of embodied data literacy. The third investigates the off-label use of pharmaceuticals and the navigation of COVID-19 vaccination decisions. At the same time, the final section considers the identification of quackery and the limits of communal epistemic authority. Across these themes, the chapter argues that the ME/CFS digital

community has developed a distinctive form of *suffering-capital,* converting lived suffering into social, cultural, and epistemic resources that reshape the field of healthcare itself.

Supplements and alternative therapies

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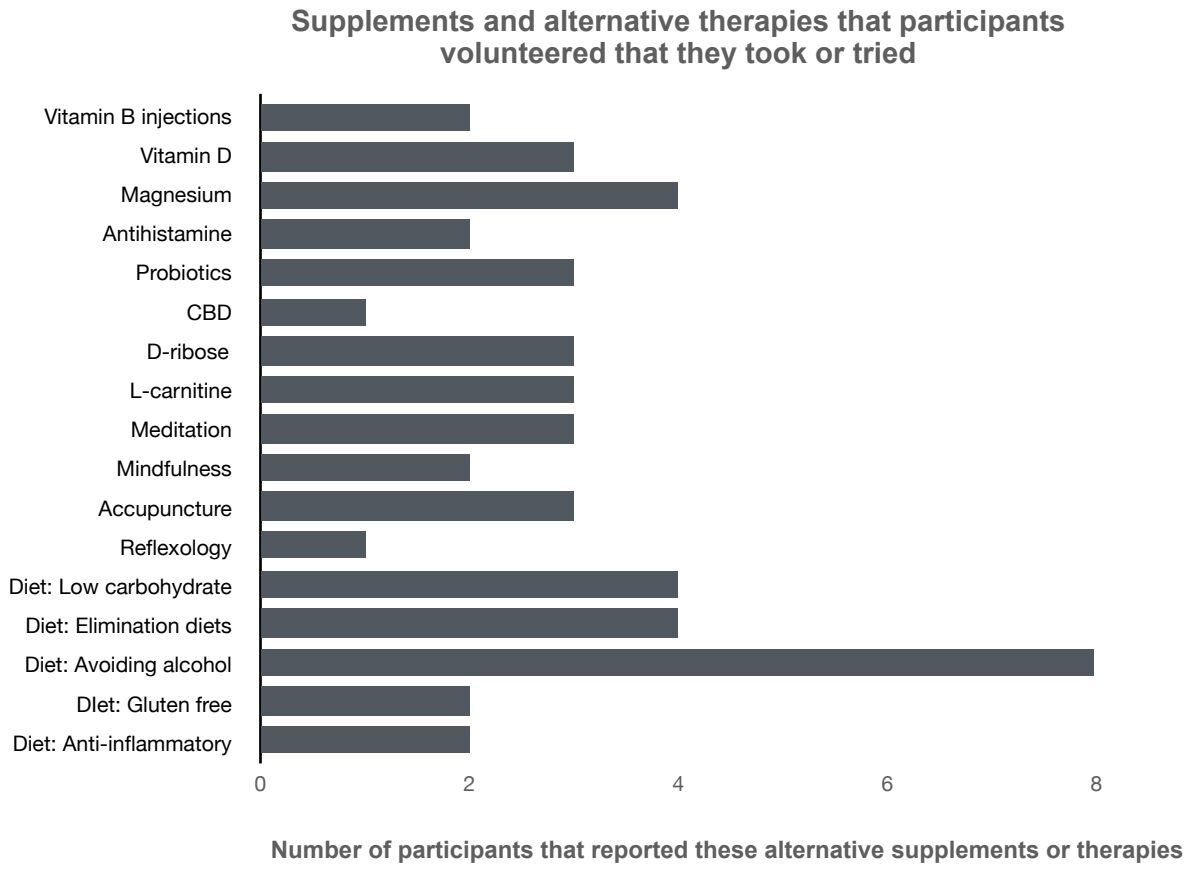
Since its publication in 2011, the PACE trial has shaped treatment recommendations for ME/CFS in the UK. It promoted Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) as effective treatments. However, as previously outlined in Chapter 1, the trial has faced widespread criticism from the scientific community and patient groups over the years for serious methodological flaws, including biased outcome reporting and inadequate objective measures. As a result, its findings have been discredited. In response to growing concerns, the National Institute for Health and Care Excellence (NICE) updated its guidelines in 2021. The new guidelines no longer recommend CBT or GET as treatments aimed at curing or significantly improving ME/CFS. Instead, CBT may only be offered as a supportive tool for managing symptoms, not as a primary treatment. The NHS has since aligned with these updated recommendations. This shift means that, as of now, there is no specific or universally accepted medical treatment for ME/CFS in the UK. With limited treatment options available, many patients are increasingly turning to home-based approaches to manage their illness. This includes the use of alternative therapies aimed at relieving particular symptoms. Within the ME/CFS community, practices such as acupuncture, massage therapy, and vitamin or nutritional supplements are widely discussed and shared. While scientific evidence for their effectiveness remains limited, some individuals report benefits in managing pain, sleep disturbances, and fatigue.

During the netnographic process, 62 conversations were reviewed as discussing supplements and alternative therapies. During these discussions, people shared links to literature supporting their positions. All 14 participants reported experiences with alternative therapies in their journals, as did all 12 participants during the interview process; these are detailed in Figure 1. Overall, these participants were favourable about the outcomes of trying these alternative therapies and supplements, with no adverse responses reported from participating in meditation/mindfulness, vitamin supplements, or acupuncture/reflexology. While many maintained these practices, those who didn’t cited financial constraints, an inability to travel to appointments, or a belief that they were helping but not enough to sustain the practice as reasons for discontinuing.

The participant who reported trying vitamin B12 injections did so after hearing about a specific doctor that she discovered in an ME/CFS Facebook forum, Dr Amolak Bansal. Dr

Bansal has been given his own page on MEPedia (MEpedia, n.d.), a community-trusted database which will be discussed in more detail in the following chapter. She described a visit to her GP's practice, where she shared information from MEpedia with her GP, who then organised a referral to Dr Bansal, whom she continues to see. Others described coming to these treatments through 'word of mouth', 'comments people were making in chats', and 'recommendations from ME charities [and organisations]'. However, half of the participants made it clear that simply hearing about a supplement in an online forum wouldn't be the only reason they would try it, nor would it indicate that it would certainly help them. Participant A articulated, 'I wouldn't take supplements that were advised by online forums alone because they don't help everybody'. This cautious pragmatism exemplifies what Bourdieu (1977) might call the reflexive dimension of *habitus*, a learned disposition towards critically negotiating advice within the field. Rather than naively adopting peer recommendations, participants exhibit embodied discernment developed through repeated digital engagement.

Figure 1



Participants reported that these practices were most beneficial for dietary interventions. Many participants believed that diet was the most important factor in managing their symptoms, relaying, 'diet is everything,' or 'the main thing I do religiously is monitor my diet,' with ten of those interviewed declaring that they believe there is a link between gut health and ME/CFS. This was a theme prevalent during the netnographic data collection, with 56 conversations recorded discussing the topic, often implying that this was a definitive fact. Interestingly, the significance of diet was frequently underscored by citing Dr Sarah Myhill, a doctor whose professional practice focuses on delivering care to patients with ME/CFS. Despite the controversies surrounding this doctor (which will be discussed in the following chapter), there was clear evidence of significant community support, as patients advocated for and adopted her dietary and gut-health practices. One of the participants who had also read one of Myhill's books stressed that it was so important because it looked at finding ways to alleviate individual symptoms of ME/CFS, for example, the digestive and gastric symptoms, which are a persistent symptom for many sufferers. She said,

> that some people were recommending keeping away from aspartame and other sweeteners, […] because they can cause, like, inflammation in your system, you know, in the gut and things and gut health would be very important for people with ME. […] So a lot of stuff like the diet, looking after the diet, and the gut health is stuff that is on the ME Association website specifically, and it is important to not always look at ME-specific stuff, but to look at general health stuff as well (Participant L).

However, this was not unanimous. One participant who has severe ME/CFS wrote in their journal;

> I've seen people in the Myhill group vehemently advocating keto as the best thing since sliced bread. I know it helps some people, but with no warning of any risks. Early on, I nearly lost my gallbladder trying [a keto diet] and had no benefit, and I know of several people who, in fact, did lose theirs. I'm now far more careful with pre-research and not just trusting tips straight off (Participant M).

This participant's experience of nearly losing their gallbladder clearly highlights how the multisystemic complexities of this illness require all interventions, even those that appear innocuous, to be managed by practitioners. Evidence of such practitioner engagement and care in this regard, was found lacking throughout the data.

When discussing her success with a gluten-free diet, one participant shared that, when she spoke with medical practitioners, they didn't value dietary restrictions as relevant in her treatment. She said,

> It's not necessarily at the forefront, but it does seem to be something that, colloquially, we as a community seem to have quite a strong knowledge of, that being a preferred diet for us. But again, it's not one of those sorts of scientifically put forward things yet (Participant A).

The idea that the community's knowledge was ahead of scientific discovery in this area was a recurring theme in discussions. This was also expressed when discussing alcohol intolerance, something referenced by eight participants during the interview process. One person highlighted the lack of awareness of alcohol intolerance by medical practitioners, stating that he had never been advised to avoid alcohol by any practitioners. He shared,

> I don't know anyone who's been recommended that through sort of NHS-type resources. I think there's a recent ME Association survey, and that suggests about 90% of people with ME are alcohol intolerant. When you're looking at that sort of percentage, why aren't people with ME being told, hey, you might have a problem with alcohol because we're not talking about 50%, we're not talking about 20%, we're talking about 90% (Participant B).

These findings reflect a growing reliance on self-directed and community-informed care among people with ME/CFS. While scientific evidence for many of these therapies remains limited, patient experiences suggest that they play an important role in symptom management.

The gap between clinical guidance and patient knowledge highlights a need for more inclusive research and greater recognition of lived experience in shaping future care. These exchanges exemplify how embodied suffering is transformed into a productive social resource: *suffering-capital*. Within these digital communities, the articulation of pain and recovery stories functions as both emotional labour and epistemic currency. Members gain legitimacy by converting lived hardship into actionable advice, thereby repositioning suffering as a means of generating value rather than merely as a marker of vulnerability.

This redistribution of authority demonstrates the reconfiguration of biomedical power, which medical or governmental authorities have traditionally held. Here, we can see that experiential knowledge is collectively validated and circulated. Taken together, these

exchanges reveal how embodied suffering is translated into symbolic and social resources, the process I have conceptualised as *suffering-capital*. Within these networks, legitimacy arises not from professional status but from the capacity to narrate collective experiences of illness as expertise. In this sense, the ME/CFS community converts suffering into epistemic value, demonstrating a reconfiguration of the medical field. As the following section will detail, these biochemical and dietary interventions are paralleled by behavioural strategies that similarly rely on shared expertise and embodied calibration. Pacing, the most widely discussed practice, demonstrates how community learning translates into self-management routines grounded in bodily awareness.

Pacing, Heart-Rate Monitoring, and Vagus Nerve Stimulation as forms of embodied data literacy

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Pacing

Along with diet, “pacing” was the most frequently discussed form of self-administered treatment. Pacing is a self-management technique used by people with ME/CFS to help reduce the frequency and severity of symptoms, especially Post-Exertional Malaise (PEM). PEM is a key feature of ME/CFS that refers to the worsening of symptoms, such as extreme fatigue, pain, and cognitive difficulties, after physical or mental activity. These symptoms can last for days or weeks and are not improved by rest alone. Pacing involves carefully planning and balancing activity with rest to avoid triggering PEM. This means staying within one’s “energy envelope,” or the amount of energy a person can use without worsening symptoms.

Pacing encourages individuals to monitor their energy levels closely and adjust their daily activities. This may involve breaking tasks into smaller steps, taking regular breaks, and avoiding pushing through fatigue. Rather than aiming to increase activity levels over time, as is the case with the controversial GET, pacing focuses on stability and on avoiding setbacks. It helps people learn their physical and mental limits and live within them. Tools such as activity diaries or wearable devices can support pacing by helping individuals identify patterns and triggers. While pacing does not cure ME/CFS, many people find it helpful for managing daily life and reducing the risk of crashes caused by PEM. The practice of pacing can be understood as an expression of *habitus* in action as a set of embodied dispositions are refined through repeated negotiation between bodily limits and social expectations. Within cyberspace, this *habitus* is shared, reinforced, and adjusted through ongoing peer dialogue.

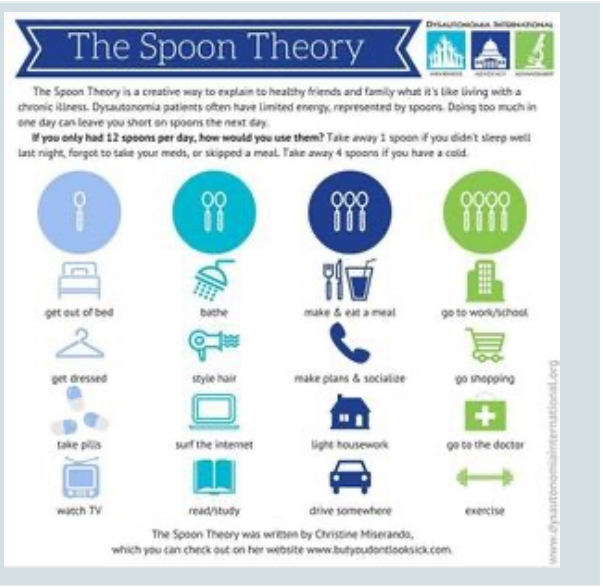
The netnographic study revealed that the “spoon theory” was used as a tool to share experiences of PEM within the community, particularly through memes that depict it. Figure 2 details some instances of the sharing of this perspective. Spoon theory is a framework for explaining the limited energy available to people with chronic illnesses or disabilities. It uses “spoons” as a metaphor for units of energy. It suggests that every activity, for example, like getting dressed, cooking, or socialising, costs a certain number of spoons. People with chronic conditions start each day with fewer spoons than healthy individuals, so they must plan carefully and prioritise tasks. Once their spoons are used

up, they cannot engage in further activity without significant consequences, such as pain, exhaustion, or PEM.

The theory helps others understand the invisible challenges of chronic illness. These memes are widely adopted, and 22 discussions included community members who suggested sending them to family members or relatives when community members asked questions such as “How do I explain that I need to pace?” or when discussing occasions when their friends and family did not believe they needed to rest. These memes function as part of a social media toolkit that patients use to communicate their lived experiences.

Three of the interviewed participants also reported that memes that explain fatigue and spoon theory are helpful for creating understanding with friends and family. One participant said, 'I just send them the spoon theory meme, it's just such a simple way of explaining the unexplainable' (Participant D). Another said, 'they just don’t understand that you can do one thing one day and not the next […] spoon theory is the only thing that is there for us to explain and say, this, look at this, I may be able to walk today or whatever, but that's borrowed from tomorrow' (Participant I). It is worth noting that wider communities with chronic illness have also adopted the spoon theory, and it is not reserved for those with ME/CFS.

Figure 2: Four examples of Spoon theory memes from netnographic data capture



One participant described pacing as

> the most important [treatment protocol], because understanding the need to plan rest breaks into every activity is essential. Also refusing graded exercise therapy, even when it was still prescribed on the NHS, greatly influenced the management of my condition for the better (Participant A).

She described visiting her local ME/CFS treatment clinic after NICE and the NHS had removed GET as a treatment protocol, yet she was still prescribed GET. She took the provided literature home and posted photographs of it in an ME/CFS Facebook forum. She detailed a process of community interaction that resulted in the ME Association being tagged in her post, which then contacted her directly to request permission to write to the ME/CFS clinic. They did so, urging them to cease the practice and stop disseminating literature on GET. When she returned to the clinic three weeks later, all literature on GET had been removed. Similar direct action was observed in the netnographic process, and on three occasions, the ME Association was “tagged” in the Facebook conversation, with the community asking them to contact clinics that were still recommending GET and to stop the practice. What is evident from community dialogue is that these clinics, which were still offering GET, were unaware that the NHS guidelines had changed and were unable to offer any alternative treatment.

Across all Facebook forums, there was clear evidence of a general and robust community rejection of GET and a preference for pacing. People were observed referring to GET as 'torture therapy', making comments such as 'They’re literally killing us', and 'They know it

makes us worse and they still make us do it. [The ME/CFS clinic] basically said to me, I have to tell you to do it because there is nothing else we can offer you […] but don't do it'. However, some of these conversations were more complex. One Facebook user posted 'Don't PACE it will make you worse', to which they received replies such as 'No GET will make you worse, pacing is a must!'. This thread garnered 154 engagements on the post, in which users provided literature on the benefits of pacing, with links to various ME/CFS charities. They also posted links to MEPedia[2] and reports on GET and the now-rejected PACE trial that advocated for it. The overwhelming community consensus supported pacing and rejected GET.

This type of discussion was recurring and provided evidence that some within the community, particularly those who appeared to have a recent diagnosis, conflated two distinct practices: "GET," which encourages increased activity, and "pacing," which encourages capping activity, as the same. The naming of the "PACE trial" is clearly unhelpful in this regard (as the trial recommends GET, not pacing). These findings demonstrate that, where this community believes pacing is effective, it is not being communicated effectively by their doctors or other medical professionals. While NICE now recommends pacing as a core component of ME/CFS care in the UK, the procedure and its definition are somewhat opaque. While this new advocacy of pacing marks positive progress in the dialogue between this community and healthcare systems, both the netnographic study and the interview process indicate that there remains some confusion about the distinction between GET and pacing, which creates an ongoing risk of harm and inconsistent treatment.

These discussions on pacing reveal that pacing is an embodied manifestation of *habitus* (Bourdieu, 1977; Crossley, 2001), as it articulates a learned set of dispositions arising from ongoing interactions among the body, social norms, and material environments. Through digital engagement, this *habitus* becomes both individual and collective as the body is not only experienced but also theorised and trained through peer exchange. The repetition of pacing narratives in online spaces demonstrates how embodied self-discipline is socially reinforced and digitally mediated, producing a shared bodily awareness that blurs distinctions between medical expertise and lived experience. These findings suggest that pacing is not merely a practical strategy but an embodied pedagogy through which patients teach one another to inhabit illness differently. The practice reveals *habitus* as

[2] The wiki for ME/CFS

collectively re-engineered through digital communication, where the body becomes both teacher and text. This exemplifies the emergence of a shared *digital habitus* that fuses corporeal discipline with online connectivity.

Heart-rate monitoring (HRM)

The emphasis on bodily calibration extends beyond subjective awareness into datafication. Heart-rate monitoring (HRM) represents an evolution of pacing's logic, translating embodied intuition into quantifiable metrics. A key discovery from the data was the hacking of fitness trackers/heart rate monitors by people with ME/CFS to repurpose the technology as a tool to help manage their symptoms, particularly to avoid PEM. However, the use of heart-rate monitoring illustrates the *pharmacological* nature of digital technology as it is simultaneously curative and toxic. While these tools empower users to self-regulate and visualise embodied data, they also risk intensifying self-surveillance and anxiety. As previously mentioned, PEM is a hallmark of ME/CFS and involves a significant worsening of symptoms following even minor physical, mental, or emotional exertion.

The principle behind HRM for people with ME/CFS is to help them remain below the anaerobic threshold, the point at which the body transitions from aerobic (oxygen-dependent) to anaerobic (oxygen-independent) energy production. For individuals affected by ME/CFS, this threshold is often lower than average due to difficulties in energy metabolism (van Campen et al., 2020). When a person's heart rate exceeds their anaerobic threshold, the risk of triggering PEM increases. A widely held view, as evidenced by numerous discussions of this topic in ME/CFS forums. 22 distinct threads focusing on the subject were documented during the netnographic process. These suggest that individuals may mitigate the potential for exacerbating their symptoms by using a heart rate monitor to remain within a "safe" range. In these forums, HRM is also considered particularly beneficial for pacing. As previously mentioned, pacing involves carefully managing activity levels to avoid exceeding one's energy limits.

It has increasingly been suggested in ME/CFS forums that heart rate monitors can serve as an objective measure of exertion, as subjective reports of energy capacity can be unreliable for individuals with ME/CFS. This is particularly evident because they often experience PEM days after an activity, making it difficult to determine which activity exceeds their threshold. Advocates of the practice suggest that HRM helps individuals identify activities that elevate their heart rate, such as climbing stairs or standing for

prolonged periods, thereby enabling them to modify or break tasks into smaller, more manageable steps. The data collected from the monitor can also unveil patterns over time, aiding patients in understanding their limits and communicating more effectively with healthcare providers. This method extends beyond physical activity; cognitive and emotional stressors can also increase heart rate. By keeping track of heart rate during mental or emotional challenges, individuals can more effectively manage different forms of strain.

Participants A, B, C, and G all mentioned discovering HRM through social media. While B and G observed discussions and posts on the subject, participants A and C engaged further. Participant C noted,

> I'm a member of an ME Facebook group and we have a monthly Teams meeting and they advertised that they were going to have a guest speaker talking about heart rate monitoring. And I thought, oh, I don't know anything about that, never come across that in my any of my research. So I joined that meeting […] So he wasn't trying to sell anything and he wasn't sort of pushing anything. He was just literally saying this is a thing that might be helpful to you people. He talked about Visible the app and the wearable, but that's quite expensive because it's a monthly subscription, he said, instead you can just buy a Fitbit. Still, obviously, they are more geared at people that are doing fitness rather than people that are really wanting to make sure the heart doesn't go above a certain thing […] but you can still manipulate the technology.

What is particularly interesting in her description is the organised nature of sharing information; the regularity of the meetings and the concept of 'guest speakers' evoke traditional educational and workplace practices. Moreover, the community's sharing of methods to navigate existing technology and repurpose it showcases apparent innovation.

Participant A described a similar introduction to the idea of HRM, something he quickly adopted by using social media groups, blogs, forums and YouTube videos to teach himself how to use a heart rate monitor to influence his healthcare protocols. He said,

> I joined a local patient-led support group for ME/CFS sufferers, and they have a Facebook page and hold regular events and meetings. I attended one video meeting, as they had a guest speaker talking about using heart monitoring as a tool for managing ME/CFS symptoms, and I had not heard about that before. It led me to look into heart rate wearables, and what heart rate variability is, and how using them can assist with patterns and activity management.

He characterised the process as ‘hacking’ existing technology, but then using it for a very different purpose than what it’s intended for. ’ He argued that while the process can be similar to an activity diary, ‘activity diaries for people with ME are exhausting and unpleasant’, as well as being flawed by subjectivity. Having found the process ‘an incredibly effective tool to help with pacing’, he has himself gone on to lead online training sessions for individuals with ME/CFS, as well as in-person training sessions that he delivers to medical professionals at his local ME/CFS clinic. However, he expressed that there is a lack of information on this practice available to both healthcare professionals, practitioners and patients. As such, he

> reached out to [anonomysed name] from the Workwell Foundation and [anonomysed name] from Physios for ME, and we ended up doing a research pilot together, and so we recruited people that would help people to use heart rate monitors. […] They were all recruited through social media forums. That’s the good thing about social media is that you can sort of tap into the experiences of other people in similar situations. I bought about 30 heart rate monitors […] and basically, I tend to buy refurbished, and they're mainly used by people who are either sports people, you know, using them for like workouts. […] These were given to the people we recruited and I trained them on how to use the heart rate monitors effectively, usually through Skype or Facebook video. So then they could go out and start training people with ME to use them via their individual networks.

Participant A acknowledged a clear need for academic research in this area for the practice to receive recognition and respect from medical professionals. Currently, there is limited peer-reviewed research on the reliability and accuracy of wearable technology and its effectiveness in measuring and monitoring symptoms of ME/CFS. Stevens and Davenport (2010) conducted a case study in which they monitored a single participant over time while they engaged in HRM. They reported significant improvements in symptoms and overall well-being. Clague-Baker et al. (2023a) recently investigated 17 individuals with ME/CFS in their homes, utilising a portable metabolic assessment system alongside a physiological stress monitor. They evaluated blood pressure, heart rate, oxygen saturation, and lactic acid while participants engaged in various daily activities. The study demonstrated that physiological measurements during these activities were reliable and called for further research to establish home-based assessment protocols that could enhance the biobehavioural understanding of ME.

To date, the only other published study on this practice reports on data from an online survey. The survey was completed by 488 individuals with ME/CFS who had engaged in

heart rate monitoring, all of whom were recruited via the ‘Physios for ME’ Facebook page, the same community to which Participant A had reached out. The survey found that HRM reduced the severity of ME/CFS, as well as the intensity and duration of PEM. They found

> HRM has many benefits, including helping PwME to understand and manage their PEM and support them to increase their activities, including work. […] It has also highlighted the need for more research and education of healthcare professionals in the safe use of HRM (Clague-Baker *et al.*, 2023b, p. 1225).

The paper by Clague-Baker et al. (2023b) reinforces the thesis's findings that many individuals with ME/CFS, through active online participation and information exchange, are collectively using the networked, participatory, and multimedia characteristics of cyberspace to create healthcare protocols, independent of traditional medical fields and authorities. Nonetheless, this community is receptive to working with academics, doctors, and healthcare professionals who are willing to engage with them, provided these authorities have both a transparent interest in the subject and a personal connection to the illness (a criterion discussed further in the following chapter).

Although most discussions of HRM focused on hacking fitness trackers/heart rate monitors, the *Visible* app was also frequently discussed in the context of HRM. *Visible* is a heart rate monitor with a downloadable app designed explicitly for people ME/CFS. On their website, they describe the product as ‘Pacing made simple’, reporting that ‘86% of members report that they feel more in control of their illness [and that] 91% of members report that they’re better able to manage their energy’ (Visible, 2024a). The business presents itself as a proposition created by people with ME/CFS. They use a screenshot from a video chat to introduce the team, see Figure 3, which shows the team all in their houses rather than an office, the predicament over 25% of people with ME/CFS find themselves in (Institute of Medicine, 2015; NICE, 2021).

Figure 3

What is particularly notable is the app's collaboration with Imperial College London, allowing users to voluntarily share their illness-tracking data directly with researchers. Harry Leeming, Visible's co-founder, reports

> I was a fit and healthy 29 year old, but a mild infection has turned my life upside down. I've now had ongoing symptoms for 3 years. The lack of recognition, support and tools to manage my condition has been alarming. With Visible, we're building a patient-powered platform to measure and manage my illness, and those of millions of others like me (Visible, 2024b).

This narrative reflects the pattern observed throughout these discussion chapters, in which patients leverage technology to construct databases of knowledge and shared experiences in response to the absence of research and treatment protocols from established authorities such as government, academia, and healthcare. Likewise, evidence suggests that trust in protocols, such as HRM and *Visible*, is linked to validation from patient communities and established actors in the field. For example, when Participant B described her discovery of HRM, she stated,

> One thing I'm I'm actually going to get it myself, so scrolling through the Internet, I don't know if you've heard about it, but there's *Visible*, it's an app. […] I was like, free scrolling and stuff, and the ME Association then wrote an article about it, like, three days after I discovered it. So there's backing to it as well. But I'm, like, spreading the word about it.

What is particularly interesting in her description is her declaration that she has already advocated for the *Visible* app before trying it, which she justifies with the ME Association's support. The significance of such support from established pillars of authority within the community was reiterated in several of the online discussions recorded regarding Visible, as evidenced by the three separate conversations outlined below;

Anonymous 1:	Is there any evidence to support that this actually works before I go spend a fortune?
Anonymous 2:	Yeah the ME association has posted loads on it have a look on their website.
Anonymous 1:	Is there any actual science behind this, something that isn't behind a paywall?
Anonymous 2:	Yea Workwell and the ME Ass have both postd quite a lot about it
Anonymous 1:	Link? :)
Anonymous 3:	https://meassociation.org.uk/2023/03/research-heart-rate-monitoring
Anonymous 1:	Am I going to regret spending money on this? NE1 actually tried it???
Anonymous 2:	Yes I tried it really helpful, this is something Dr Charles has endorsed HRM wont regret it If you can't afford Visable there's a guy on Youtube that teaches you how to adapt a Fitbit.
Anonymous 1:	Nice. I'll give it go. U got a link to the vid?

These dialogues illustrate community members seeking both evidence and authority before adopting new practices. They also reflect community agreements on what constitutes authority and who holds it. What emerges here is a striking illustration of the *pharmakon* quality of cyberspace (Stiegler, 2011): a medium that simultaneously enables care and cultivates anxiety. Heart-rate monitoring empowers patients to visualise their suffering and gain control, yet it also reproduces surveillance logics that risk intensifying self-blame. This duality mirrors the broader tension within digital health citizenship discussed in Chapter 2.

Vagus Nerve Stimulators (VNS)

While pacing and HRM reconfigure everyday practices of care, the community's interest in vagus nerve stimulation (VNS) is pushing further toward biomedical experimentation. Here, the drive for innovation collides with questions of safety, authority, and ethics. Vagus nerve stimulators are gaining attention in ME/CFS Facebook groups. The vagus nerve plays a crucial role in relaxation and various bodily functions, connecting the brain to the

abdomen and regulating heart rate, digestion, and immune responses. Its balance is key for the autonomic nervous system, which governs involuntary functions. Vagus nerve stimulation is being explored by people with ME/CFS due to its effects on inflammation and autonomic balance. Many ME/CFS patients experience an overactive sympathetic and underactive parasympathetic system, leading to exacerbated symptoms. In ME/CFS Facebook forums, it is frequently suggested that VNS may help restore this balance, promoting relaxation and recovery by reducing the inflammation associated with ME/CFS symptoms, such as fatigue and cognitive difficulties, while enhancing communication between the brain and gut.

Despite observing 37 discussions about VNS during the netnographic process of this study, very little research has been published in this area. A small study involving 14 participants examined VNS for individuals with ME/CFS and found that eight of them experienced benefits for their daily symptoms, including PEM (Natelson et al., 2022). VNS is currently used for certain types of epilepsy and depression, however, there is increasing interest in vagus nerve stimulation for ME/CFS, and the evidence is still developing. Accordingly, the practice appears to be primarily based on anecdotal reports within the online community.

There are several methods to stimulate the vagus nerve. ME/CFS communities typically utilise non-invasive VNS devices, such as TENS machines, which are traditionally used to deliver electric shocks to the body for pain relief. These devices stimulate the vagus nerve through the skin, typically on the neck or ear. It is important to note that while generally safe, a TENS machine can cause harm and pain, and even trigger seizures if misused (Minnis, 2024).

During the interview process, it was revealed that six participants were planning to try VNS, while participants E and H had already tried it. Participant E reported being introduced to the idea through a Facebook forum and shared a mixed experience with the process.

> Yeah, but the first thing I did —you know, I can't believe I did this — because I was a research scientist, among other things. So for me, you absolutely do science in a certain way. And yet, as a person with ME, so desperate is the illness that my training, my career, and my experience go out the window. I was online one day, and there was all this stuff about this TENS machine that you clip on your ear, and it electrically massages your vagus nerve or whatever we call it. And I just ordered

> one, you know? I got it, didn't read the instructions, stuck it on, turned the pain up until I couldn't bear it, and then just turned it down a bit. I managed about five minutes with it. I took it off, and this is God's honest truth: I was just laid in the fetal position for 24 hours; the pain was astonishing. Uh, but I did feel better afterwards. I did get improvement, but the next time I read the instructions (Participant E).

Participant E reported some success from the treatment; however, they also experienced harm during the process. Despite this participant's scientific and research background, which may make them more equipped than most to responsibly trial VNS, their desperation from suffering with ME/CFS ultimately overshadowed their reasoning. Where they noted that the next time they used it, they would 'fully read the instructions,' their experience clearly highlights the potential dangers this community faces due to a lack of scientific research.

Participant H adopted a more strategic method in testing the device. She initially learned about it through a link shared in a Facebook group. Subsequently, she joined a specialised Facebook group that serves as a discussion forum dedicated to vagus nerve stimulation. After engaging with group members and asking questions, she conducted further research and discovered an Australian physiotherapist who had published studies on VNS. Armed with this information, she consulted her GP to discuss the possibility of trying it out, and they concluded that a trial would be beneficial. She explained, 'So I bought the device, but I obviously overused it. Although I followed what the company told me to do, it actually triggered a lot of trauma with me.' It was noteworthy that she felt responsible for the mistake of overusing the device, even though she had adhered to the guidelines and used it in accordance with the manual. This experience underscores the vulnerability faced by this population when navigating treatment protocols, along with the burden of responsibility that comes with the potential for causing self-harm.

While the netnographic process revealed much positive dialogue about the treatment potential of VNS, and it was clearly sufficient to encourage many community members to act as early adopters to test the technology, there were also significant discussions that tagged authorities such as the ME association and Physios for ME, urging them to engage in scientific research. Shortly after completing the first stage of netnographic data collection for this study, Physios for ME responded to these community requests to review VNS usage in order to create authoritative knowledge about the protocol. The study

recruited 116 participants from Twitter and Facebook ME/CFS forums and websites, asking them about their experiences with VNS. They found,

> 56% of respondents reported favourable effects. Benefits of transcutaneous auricular vagus nerve stimulation were identified in relation to post-exertional malaise, pain, gut problems, urinary problems, mental health, and the ability to leave the house. 67.2% of respondents would recommend the intervention to other people with ME (Leslie *et al.,*2023, p. 32).

This mirrors the protocol outlined in the exploration of HRM. The community utilises digital networks of individuals with ME/CFS and collaborates with professionals who have both expertise and lived experience, either personally or through a close friend or relative. The research conducted was organised in direct response to the community's expressed need for credible research on the subject. What is perhaps most concerning about these findings is that 6% reported it made their condition worse (ibid). As previously highlighted, repurposing a TENS machine could potentially cause harm. Given the lack of guidance from experienced medical practitioners on how to use this technology, and the fact that people with ME/CFS are using these devices privately and without monitoring, there is clear scope for further research and monitoring in this area. While HRM is non-invasive, enabling patients to engage with technology passively, VNS is a significantly more invasive intervention. Additionally, there is a concerning lack of research, and this study has found evidence that some patients are attempting to use VNS in harmful ways.

Although my netnographic research concluded over a year ago, I utilised my personal Facebook profile during the study. Now, a year later, my account is frequently targeted by algorithms promoting VNS devices. I now receive recommendations and advertisements for various vagus nerve stimulators, often accompanied by claims about their safety and extensive research for individuals with ME/CFS. This is concerning, given the limited research surrounding VNS's application for ME/CFS. The naturalisation of VNS messaging may normalise the pursuit of these devices, and claims about their effectiveness for people with ME/CFS may influence a less rigorous consulting and evaluation approach than is characteristic of this community. While one of this community's strengths is its eagerness to experiment with healthcare protocols and share results, it also creates potential safeguarding risks. Those eager to try anything for better health may inadvertently engage in trials that could be harmful.

This ambivalence again highlights the *pharmacological* quality of digital technology as it functions simultaneously as cure and poison. HRM empowers users to visualise and legitimise their embodied experiences, yet it also extends medical surveillance into domestic and affective spaces. The same tools that offer control can therefore reproduce cycles of self-blame and hypervigilance, reflecting the paradox of the digital *pharmakon*. This tension underscores how the ME/CFS digital *habitus* is continually negotiated between empowerment and anxiety, visibility and vulnerability. The community's engagement with VNS reflects the limits of patient-led experimentation: where institutional absence fosters creativity, it also heightens vulnerability. This oscillation between empowerment and exposure embodies the digital *pharmakon* in its fullest sense as both cure and poison are entwined. Moving from devices to drugs, the following section explores how participants extend their experimental ethos into pharmacological domains, navigating the blurred boundaries between medical sanction and community-driven innovation.

Off-label use of pharmaceuticals and the navigation of *COVID-19* vaccination decisions

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Off-labelling pharmaceuticals

Off-label medication refers to the use of a medicine in a manner that differs from its official approval. When a drug is licensed in the UK, it has been tested and authorised by regulatory bodies such as the Medicines and Healthcare Products Regulatory Agency (MHRA) for specific conditions, doses, or age groups. However, doctors may sometimes prescribe medication for a different purpose, dosage, or patient group than is stated on the label. This practice is called off-label use. Off-label prescribing is legal and relatively common in the UK, particularly when no approved treatments exist for a condition or when a doctor believes a medication could be beneficial based on clinical experience or research. It is frequently utilised in areas such as rare diseases, mental health, or chronic illnesses like ME/CFS, where treatment options may be scarce. When prescribing off-label, doctors must consider the safety and effectiveness of the medicine for the new use. They are expected to base their decision on the best available evidence and to discuss the risks and benefits with the patient. Informed consent is essential, meaning patients should understand that the medicine is being used outside of its official license.

Something that was revealed as particularly prevalent in the Facebook forums I explored was the mention of LDN, which refers to low-dose Naltrexone, a drug licensed to treat alcohol withdrawal. The effectiveness of this medication at very low doses remains anecdotal, although randomised trials are underway. Participant M, who came to LDN after reading journal articles about the drug that had been shared in a severe ME/CFS forum, expressed uncertainty about how effective taking LDN has been for them. Still, they wanted to try it because they believe that experimenting with these options and reporting the effects, even if they aren’t substantial, benefits 'idea generation'. She felt that generating knowledge about whether it helped her or others was reason enough to try the drug. Participant J also reported trying LDN. She downloaded journal articles from social media forums and took them to her doctor, with whom she evaluated taking the medication. The doctor agreed to prescribe it, with regular follow-ups, and they found the medication to minimise some of their ME/CFS-related symptoms significantly.

LDN wasn’t the only medication mentioned. Participant D discussed experiences where his doctor's lack of knowledge about the multisystemic nature of ME/CFS meant that they

had to intervene and advocate for alternative medications to avoid potential harm. He shared,

> I had an appointment on Monday with the cardiologist, and he was going to prescribe me [a certain drug]. I persuaded him instead to prescribe something else. I showed him my heart rate data from my, you know, monitoring myself, but also some data from different people who were also heart rate monitoring. I also showed him various research and other things I had gathered from forums, you know. It was a mixture of community feedback and research that led him to give me the drug that I wanted, which was going to help more. It was through videos that were put together by and for the patient community that I found easier to understand than some of the more technical materials. This helped me come in well-armed with insights from the community about what had worked for others. I was able to have a conversation with him to walk through different options and discuss why I thought one thing was better than another. In this case, the drug he wanted to give me raises blood pressure, and due to my ME, I'm hypertensive, which could likely cause more problems than it would solve. The drug I wanted them to consider was likely to actually lower my blood pressure and heart rate and was more likely to be effective. So it kind of gave me the confidence to argue for what I wanted, and it did work as I expected.

Participant D's account of it being the combination of both patient reports combined with medical research that persuaded his doctor to deviate and try a new treatment plan was reassuring and demonstrates the openess of medical professionals to listen, however, it does highlight the extent to which the doctor-patient relationship can impact the care of individuals in this community, highlighting how those with the skill set and capacity to advocate for themselves convincingly, appear to fair better at influencing their healthcare.

Participant J had researched several medications. After finding some success with LDN, she also brought evidence to her doctor to convince them to allow her to try Amitriptyline. She shared,

> Amitriptyline is the only medication that they were happy to prescribe without specialist intervention. Since starting it, my M.E. has improved enough that I went from being unable to bathe myself to having a shower once, sometimes twice, a week. Even though it's for mental health, I didn't expect it to help with my mental health at all, but it has improved dramatically. Now, however, I'm dealing with a new doctor who keeps trying to pressure me to come off Amitriptyline because they've decided a stronger antidepressant would be better for my mental health, despite knowing it will worsen my M.E.

This participant's experience again highlights how a change in doctor can cause significant anxiety. She furthered, 'It's like she has an agenda against Amitriptyline' despite her

patient pleading that this medication was never prescribed for mental health issues. This also clearly plays into the historical and outdated categorisation of ME/CFS as a mental health concern, rather than as a physiological condition, highlighted in chapter 1.

What is clear from these testimonials is that access to these off-label medications wouldn't be possible without the community-gathering of digital information banks. The best results were achieved when community knowledge was shared with physicians who actively worked with their patients and monitored them to identify interventions that alleviated their symptoms. These collaborations clearly weren't all successful; however, the collaboration process itself seemed to strengthen understanding between doctors and patients.

Nevertheless, the onus remains very much on patients to take the lead. Indeed, in the netnographic data, one community member reported that her 'GP called me up and asked me if she could give my number to another patient […] because I know more about ME/CFS than they do and they didn't want to give the patient any bad advice about medications'. While it's encouraging to hear doctors listening to their patients and including their lived experiences to build on their epistemological knowledge, this GP's action is clearly inappropriate and demonstrates the lack of research surrounding all aspects of this illness.

While off-label use can provide valuable options, it also highlights the need for more research and approved treatments for complex or poorly understood conditions, to prevent this community from continuing to serve as random, undocumented guinea pigs, with valuable knowledge and insights about both harmful and curative outcomes being wasted. What, however, emerges from this example is a form of collective agency that extends beyond patient self-help into field transformation. By collating, interpreting, and testing biomedical information, patients enact a redistribution of epistemic power. Their digital practices challenge the symbolic boundaries of the medical field, compelling professionals to recognise patient expertise as a legitimate form of knowledge production. This shift reframes the ME/CFS community not merely as a population of sufferers but as active participants in the co-production of medical knowledge (Epstein, 1996; Callon and Rabeharisoa, 2008). This negotiation between patients and practitioners reconfigures what Bourdieu (1990) would term the *field* of medicine itself. Authority is redistributed through digital mediation as patients accumulate symbolic and epistemic capital by mobilising collective knowledge. The result is a form of collaborative medical *habitus* that unsettles

the asymmetry of traditional doctor–patient relationships. These redefinitions of expertise became particularly visible during moments of public crisis. The COVID-19 pandemic offered a test case for how community-generated epistemic authority operates under institutional uncertainty.

COVID-19 Vaccinations

Although my netnographic research took place post-COVID-19 and, therefore, discussions about COVID-19 vaccinations weren't prevalent in online forums, seven participants mentioned using social media to evaluate vaccination protocols within their journals and during the interview process. When the first COVID-19 vaccinations were introduced in the UK, certain groups deemed most vulnerable in society were prioritised, before they were made available to the wider population. Vulnerable categories were defined by the Joint Committee on Vaccination and Immunisation (JCVI), an independent advisory committee. Local doctors then allocated their patient lists accordingly. People with ME/CFS were not detailed explicitly on any of these lists; however, there was room for practitioners to add their patients to vulnerable groups based on their clinical judgement. This meant that the quality and familiarity of the relationship between patients with ME/CFS and their local doctors, and, indeed, their doctors' professional understanding of ME/CFS, had a marked impact on whether patients were deemed vulnerable enough to receive vaccinations.

As ME/CFS is a multisystemic illness and is considered a spectrum disorder, some patients experience extreme symptoms triggered by their immune system. In contrast, others may have more pronounced symptoms, such as neurological or cardiovascular issues. Additionally, the range of severity is wide; therefore, while certain medical interventions may significantly affect some patients, they may have minimal effects on others. The participants who discussed COVID-19 vaccinations expressed uncertainty and apprehension about receiving them. One participant described her onset of ME/CFS as a result of receiving the HPV vaccination when she was a teenager. While she acknowledges that this has 'never been corroborated by a doctor,' she and her mother, her primary carer, have repeatedly raised it with her GP. She chose to receive the COVID-19 vaccine based on her physician's recommendation and guidance from the ME Association. She said,

> There was quite a push for people to take the vaccinations, even the ME Association. One of [the ME Association's] resident doctors is quite keen on you know pushing people with ME to have, you know, encouraging them to have the

> jabs, even though, as I say in my personal experience, you know that would not be a good idea. But you know, obviously, with his background, he was […] enthusiastic for people to get it (Participant L).

However, for her, taking the vaccine caused a significant worsening of her ME/CFS symptoms, and she experienced a prolonged immune response to it. For her, this really highlighted the lack of knowledge her doctor held about how her illness manifests and a denial of her lived experience, despite her eagerness to share her knowledge and expertise of her illness with her doctors.

Another interviewee also highlighted the importance of the doctor-patient relationship in this regard. She shared,

> When the pandemic broke out, my doctor wrote a note for me and basically advised me that I should be classed as clinically extremely vulnerable because of my ME. And, when I did catch COVID, I had an immune reaction which I nearly died from. So they did say in the hospital, and I believe that they wrote in my records that if I were to catch COVID again, well, they said to avoid catching anything until my immune system bounced back and certainly not COVID again, because they did say I might not survive it a second time. But if I were to catch it again, then I am now eligible for antivirals. But that's only because of the really terrible reaction and how poorly I was with it. Rather than the recognition of the underlying condition (Participant A).

Participant A's experience demonstrates the lack of consistency in the healthcare profession, where her GP may fully recognise that ME/CFS is multisystemic and engages the immune system in certain detrimental ways, but the hospital that treated her for COVID didn't recognise ME/CFS as being a potential factor in how a patient may respond to the challenge of COVID-19. She added,

> I wasn't believed, and ultimately that's how I got sick in the 1st place. So it has been a difficult time for everybody. But I do think within our community, this not believing us, thinking it's in our heads, or you're overreacting to something, has really manifested, and we've seen that in society (Participant A).

Her sentiments are in line with the narrative widely adopted within the community, that there is still a strong branch of the medical profession failing to recognise the physiological nature of the condition. Both these participants also highlight that while the ME Association is a trusted source of information for them, there is a limit to that trust, and for some patients, an element of scepticism of any authority remains.

This wasn’t the case for all interviewees. Participant E focused more on the collaborative approach of the ME Association in their navigation of discussions about COVID-19 vaccinations. They shared,

> I think certainly during COVID, I seem to remember, I think it was the M.E. Association, they seem to be quite hot on it, that they were kind of publishing things or trying to, like, get an idea of if people are having reactions to vaccinations and things like that. So that was quite useful, because actually, [my housemate who also has ME/CFS] had a really severe downturn in her ME following her first COVID vaccination (Participant E).

Participant E therefore found the ME Association’s real-time online polling of the community’s response to vaccination very helpful in evaluating whether to take the risk of vaccination. She was aware that her flatmate’s response to the vaccination could be due to her flatmate’s particular immune response symptoms that she experiences with her ME/CFS, and that her own illness may not replicate the same response. Their GP had told them that they were unsure whether they should be classified as vulnerable to receive the vaccination. This was not unusual; three other participants also said their GP had no protocol for people with ME/CFS at the time when the vaccination was being administered solely to those deemed the most vulnerable. She reported that she used polling data from the ME Association to persuade her GP that she should be classified as vulnerable so that she could receive the vaccination. A decision that she was glad she made.

This sentiment was also reflected in Participant H, who stated that the polls run by the ME Association to crowd-source community responses to vaccination were extremely helpful. They shared,

> I've had multiple health professionals telling me that ME doesn't make me vulnerable enough to qualify for the COVID-19 vaccine, but also a couple saying I shouldn't have it because it makes me so unwell each time. It never seems to occur to any of them that I might have made my decision based on what data could be gathered from the ME community and on the knowledge I have about my own reactions to previous viruses and vaccines (Participant H).

Like others, they described a decision-making process in which they monitored polls conducted by both the ME Association and other community online forums, which they combined with their lived experience. What is striking in their recollections is the lack of consistency in the recommendations they received from healthcare professionals regarding the severity and characteristics of ME/CFS.

It is important, however, to acknowledge that at the onset of the pandemic, there was widespread concern across all communities, and little was known about how the virus or any developed vaccination might affect individuals, irrespective of underlying pre-existing health conditions. In retrospect, however, it can be acknowledged that the ME/CFS community was perhaps astute to crowdsource and share data in this manner.

The relationship between ME/CFS and the response to COVID-19 vaccination is an emerging area of study, particularly as the long-term effects of COVID-19 become clearer. Recent studies indicate a significant overlap between the lingering effects of COVID-19 and the symptoms of ME/CFS, especially regarding PEM. Davis et al. (2021) observed that many survivors of COVID-19 frequently report the exacerbation of symptoms after engaging in cognitive or physical activities, reminiscent of the PEM seen in ME/CFS patients. Furthermore, research by López-León et al. (2021) revealed that a substantial number of individuals suffering from what is now commonly referred to as Long-COVID experience fatigue, cognitive issues, and sleep disturbances, which closely align with ME/CFS symptoms, suggesting a potential rise in ME/CFS cases as a consequence of the pandemic. In addition, the COVID-19 vaccination has elicited a complex range of responses among ME/CFS sufferers. According to a study by Strain et al. (2022), the reactions to the vaccine vary significantly within this group. Their survey indicated that 17.9% of respondents reported a significant worsening of their ME/CFS symptoms post-vaccination, whereas 59% reported an improvement, highlighting the variability in vaccine reactions and the intricate relationship between vaccination and post-viral conditions.

The experiences of participants with ME/CFS during the COVID-19 vaccination rollout illustrate the challenges faced by a community historically marginalised within mainstream healthcare. Their decisions about whether or not to receive the vaccine were shaped by a mix of medical advice, lived experience, and peer-led support. A key theme that emerged was the inconsistency in clinical recognition of ME/CFS as a condition warranting priority vaccination. While some participants benefited from empathetic and informed GPs who advocated on their behalf, others encountered indifference or disbelief, leaving them to navigate these decisions primarily on their own. In this context, engagement with the ME/CFS community proved to be not only valuable but essential. Participants such as E and H demonstrated that real-time polling and shared experiences within forums and through organisations such as the ME Association filled a crucial informational void. These community-driven resources enabled patients to critically assess risks, challenge medical

uncertainty, and, in some cases, successfully advocate for themselves within healthcare systems that lacked formal protocols for their condition.

Moreover, the collective insight of the ME/CFS community provided a form of experiential knowledge that many participants found more trustworthy and relevant than the inconsistent guidance from professionals. The sense of validation and solidarity derived from this peer engagement helped mitigate feelings of isolation and disbelief, which are common in the ME/CFS experience. These narratives underline the importance of integrating patient voices into healthcare decision-making and public health policy.

These findings suggest that engaging with communities such as those living with ME/CFS cannot only improve individual outcomes but also foster a more inclusive, informed, and responsive health system, particularly during crises. The pandemic, therefore, intensified the community's dual positioning as both vulnerable subjects and knowledge producers. Their collective data-gathering and decision-making further illustrate how *suffering-capital* functions as a mechanism of solidarity and survival within digital health citizenship. Yet the same digital affordances that enable collaboration and data sharing also render communities susceptible to misinformation and exploitation. The following section examines how epistemic authority can fragment under the pressures of algorithmic amplification and economic opportunism.

Identifying quackery

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The uncertainty surrounding the causes of ME/CFS, along with its diverse symptoms, leaves individuals with this condition especially open to pseudoscientific claims and alternative treatments commonly labelled as quackery. Misinformation, public perception, and the scientific confusion around ME/CFS exacerbate the vulnerability of these patients, resulting in the potential exploitation by practitioners who lack evidence-based methods. Ismail et al. (2024) emphasise that during the COVID-19 pandemic, health-related misinformation escalated, complicating health communication and increasing the likelihood that individuals would seek unverified treatments. They note that to understand the prevalence of online health misinformation before, during, and after the COVID-19 crisis, it is essential to adopt a tailored strategy that takes into account socio-cultural factors and the unique experiences of affected groups, including those with ME/CFS. Patients often turn to alternative narratives due to a shortage of clear answers from conventional medical systems, which can be misleading, particularly as these narratives are widely promoted via social media. This perspective is supported by research in health communication, revealing that patients with chronic illnesses are prone to seek alternative explanations and solutions, further underscoring the vulnerability of ME/CFS patients to deceptive information (Santhouse et al., 2010).

Unverified claims frequently shape media portrayals of ME/CFS. Knudsen et al. (2011) conducted a content analysis, revealing that many media representations emphasise alternative therapies while minimising the importance of scientific treatments. This type of reporting can mislead patients and the general public, encouraging those with ME/CFS to pursue ineffective remedies that could worsen their condition. Where this chapter has previously discussed how many alternative treatments, such as massage, acupuncture, and vitamin supplements, have provided some positive relief for this community, those interventions are primarily passive in their approach. It has also discussed how off-label medications and hacking existing technologies are drawing attention from both the patient community and scientific fields. However, in seeking relief from their symptoms, the internet offers easy access to alternative, non-evidence-based “treatments” which hold the potential for harm either physically, emotionally or financially. Where this research has argued that this patient community are distinctly bio-social and has organised to create treatment protocols, it must also be acknowledged that the community are not one homogenised group, nor are these communities fully resilient to the characteristics of

cyberspace, which are both prone and mechanised to reinforce *doxa* (common-sense beliefs that may lack epistemological rigour).

Eight of those interviewed stated that they either never or rarely noticed harmful content posted in ME/CFS online forums. Two mentioned that if they did, they would ignore it, while others indicated that they would either 'always leave a comment correcting the misinformation' or 'signpost to credible information sources.' One participant shared that they think, 'it is really difficult to spot quackery'; however, she adopts the principle of only listening to healthcare protocols from people who have credentials. She said,

> I think it's really difficult, but number one, I expect them to have qualifications, so like a Doctor or a consultant dietitian rather than a nutritionist. Like if anyone's […] saying OK, come off all dairy, come off all gluten, come off blah de blah. Whatever. Any sort of that alarmist stuff […] I have a consultant and a doctor that I can completely trust. So someone else is saying something different, I'll go well, no, I've checked this with my consultant (Participant G).

This process of cross-referencing with medical professionals aligns with previous observations in this study, where people with ME, despite a lack of medical support, make efforts to have procedures and protocols validated by experts, as well as those with lived experience. However, during the netnographic process, there were occasions when community members were observed posting misinformation or promoting treatment protocols without scientific evidence. One such treatment is known as the “The Lightning Process” (TLP). TLP is an expensive therapy based on neuro-linguistic programming and cognitive behavioural therapy principles, and it maintains that mental states have a direct influence on physical health. Where there are widely accepted links between positive mental health as a correlator to improved physical health, there is no scientific evidence to suggest that positive mental health alone cures physical ailments.

Costing around £1500 for initial treatment, many people with ME/CFS continue to try TLP and 17 mentions of TLP were noted during the netnographic process. While some community members offered critiques of the effectiveness of this intervention, others stated that 'it was worth trying anything' or that 'unless I try everything available, I feel that there is more that I could be doing to dig myself out of this hell.' Another commentator mentioned that she felt she had to 'try it or her family was going to give up on her'. The financial sacrifice was also noted by some who mentioned, 'they will have to get a loan out [to pay for it],' or that they, 'had to borrow money [from family],' despite the process being

comparable to cognitive behavioural therapy, which is currently offered for free by the NHS. Talking about the Lightning Process during an interview, one participant shared,

> My instinct is that anything that feels like it's just trying to get money out of you and is something to be wary of it just anything that claims to a miracle cure, because if there was a miracle cure, we would know about it and it would be scientifically proven (Participant E).

While this may be a reassuring approach, it is likely to be an approach based on the individual's media literacy and character.

Another noteworthy factor is how general literacy and education impact an individual's ability to identify harmful content. Participant M had severe ME/CFS and was too disabled to take part in the interviewing process, so their contribution was sourced solely from their journal. When describing how they investigated treatment protocols and evaluated which ones they would like to try, they detailed a lengthy process of reviewing peer-reviewed journals, engaging with literature provided by ME/CFS charities, and utilising online forums to learn about the experiences of other patients. Their work and effort were impressive and extensive, and they detailed the journals and books they had downloaded and purchased over the past decade. However, despite this participant being well-informed about the scientific research on the illness, upon reviewing their sources, there were areas where quackery had been blended with credible discoveries. For example, they were keen to evangelise the work of a particular scientist, Dr Judy Mikovits.

Mikovits is a virologist who published a study claiming that XMRV was the cause of ME/CFS. Evaluation of her study found her findings to be compromised by contamination and a lack of reproducibility, ultimately leading to the retraction of the study and raising questions about the validity of the underlying data. She was subsequently removed from her academic role and is now a leading figure in the anti-vaccination movement (Cohen and Enserink, 2011; Neil and Campbell, 2020). The effect of Mikovits's claims on the ME/CFS community has been multifaceted, promoting both interest and confusion about the disease's aetiology. Her supporters claim that she has highlighted the struggles faced by ME/CFS patients and emphasised the necessity for more research. However, some warn that her focus on viral causes may distract from recognised biological and psychosocial models of the condition. Moreover, the ethical dimensions of Mikovits's claims demand attention. Maintaining patient welfare should be paramount within healthcare advocacy.

Yet, her controversial position raises concerns about epistemic injustice, in which patients may be misled about the nature of their illness and appropriate treatments (Blease et al., 2016). Nevertheless, Mikovits is both a doctor and a published researcher, and, understandably, some ME/CFS community members still show interest in her work, which demonstrates that even those with a solid level of academic literacy and research skills can be misled by misinformation. The persistence of such pseudoscientific content reflects the dynamics of *digital habitus* and *platform power* discussed earlier (Couldry & Hepp, 2017; Bucher, 2018), in which algorithmic amplification and networked validation shape perceptions of what is credible knowledge.

Considering these factors, it is crucial for both medical professionals and patients to navigate the complexities of ME/CFS with informed scepticism towards non-evidence-based treatments. A concerted effort by healthcare providers to present cohesive, understandable information about ME/CFS could help mitigate the impact of misleading health claims. There is growing recognition that improved communication and patient education are necessary to empower individuals and reduce susceptibility to the allure of quackery (Millar, 2022). The uncertainty related to ME/CFS complicates diagnosis and treatment, paving the way for misinformation and exploitation. As the prevalence of fraudulent treatments being peddled through cyberspace rises, patients increasingly risk making poorly informed decisions that could harm their health. Future initiatives must focus on evidence-based communication strategies that clarify the facts about ME/CFS and actively address misinformation, highlighting the critical need for media literacy within this community, particularly in light of the deficiencies in epistemological research and resources.

The circulation of misinformation within ME/CFS spaces illustrates once again the *pharmacological* duality of digital platforms in that they serve as both spaces of care and vectors of harm. Algorithmic amplification reinforces *doxa*, the taken-for-granted assumptions that normalise certain discourses and marginalise others (Bourdieu, 1990). Consequently, even communities built upon epistemic resistance remain susceptible to the structural logics of visibility and virality that underpin digital capitalism (Bucher, 2018). Recognising this tension is essential to understanding how patient-led innovation coexists with epistemic vulnerability. Indeed, the coexistence of rigorous self-education and susceptibility to quackery underscores the paradox of digital knowledge production. Within these spaces, *doxa* is continually reinforced and contested. This tension reaffirms the

community's entanglement with the digital *pharmakon*, where empowerment and endangerment remain inseparable. Collectively, the themes presented in this chapter demonstrate how ME/CFS communities are not merely responding to medical absence but actively re-making the terrain of care. The following summary synthesises these empirical insights and positions them within the broader conceptual argument of this thesis.

Summary

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These findings illustrate how individuals with ME/CFS are harnessing the distinct characteristics of digital platforms, such as interactivity, peer-to-peer exchange, rapid dissemination, and user-generated content, to curate healthcare protocols that aim to alleviate the symptoms of a poorly understood and often medically neglected illness. In the absence of definitive clinical treatments, patients with ME/CFS have turned to the affordances of social media and digital communities to collectively generate, trial, and disseminate symptom-management strategies. This aligns with a body of existing literature indicating that patients, particularly those with chronic health conditions, utilise the internet to research their conditions (Moreland et al., 2015; Chen et al., 2018). These include dietary interventions, pacing, heart rate monitoring, vagus nerve stimulation, and off-label pharmaceuticals. These findings also highlight that the participatory nature of digital platforms allows for the rapid circulation of experiential knowledge, the mobilisation of community-led research, and the construction of epistemological authority through shared validation and support. However, this same structure also introduces significant dangers, including exposure to misinformation, exploitation, and unsafe medical experimentation.

These findings demonstrate how the ME/CFS community has emerged not simply as a group of sufferers but as an epistemic network capable of interrogating scientific literature, coalescing around trusted figures, and generating collective treatment strategies. As evidenced by the use of supplements and dietary changes, as well as the adoption of protocols promoted by figures such as Dr Sarah Myhill, the community does not passively consume information. Instead, they evaluate it through communal dialogue and lived experience. This is further evident in the strategic use of tools such as heart rate monitors, which are repurposed from fitness culture into clinical instruments, and in the development of protocols such as pacing, an approach the community has championed despite inconsistent medical endorsement.

These practices demonstrate an ongoing effort to transform platforms traditionally used for social engagement into sites of bio-social innovation. They also render visible the social mechanisms through which *suffering-capital* circulates. Recognition, reciprocity, and visibility function as currencies within the field, sustaining engagement and legitimising authority. In this sense, digital labour operates both affectively and epistemically, converting lived distress into shared expertise.

Cyberspace has also enabled individuals with ME/CFS to take on roles traditionally reserved for clinicians and researchers. For example, Participant A's leadership in HRM training and in participant-led trials of VNS illustrate that patients are not only participants in care but also producers of biomedical knowledge. These practices challenge existing hierarchies of expertise by positioning patient communities as credible epistemological agents. Nonetheless, the fragility of these knowledge producers must be recognised. Their authority often relies on sustained engagement and *suffering-capital*. Should such actors become unwell, lose credibility, or exit the space, the community risks epistemic disruption.

While the ME/CFS community's use of cyberspace represents a powerful model of grassroots medical agency, it is not immune to the broader limitations of these environments. As discussed, the algorithmic nature of social media, along with the absence of robust gatekeeping, facilitates the circulation of harmful content and "quackery." From the evangelical promotion of the Lightning Process to ambiguous scientific figures like Judy Mikovits, the community must continually negotiate between credible innovation and pseudoscientific risk. This balancing act is further complicated by the varying literacy levels within the community and the persistent desperation of many members. Indeed, eHealth literacy has been linked to more informed health information-seeking behaviours (Ng et al., 2021). Although the community has developed mechanisms for internal regulation, such as cross-referencing, peer rebuke, and the elevation of trustworthy authorities, these safeguards are not consistently applied or understood. The danger is that the same openness that facilitates collaborative knowledge-building can also expose individuals to exploitation and harm.

The COVID-19 pandemic amplified these dynamics. The absence of formal clinical protocols for ME/CFS patients during the vaccine rollout revealed significant inconsistencies in healthcare delivery and highlighted the importance of community-sourced data. Real-time polling by organisations such as the ME Association became crucial for patients making high-stakes decisions amid contradictory medical advice. These practices, again, demonstrate the community's capacity to respond adaptively and innovatively to public health crises, while also underscoring its reliance on self-management amid institutional neglect. These findings suggest that the ME/CFS community exemplifies a distinctive mode of digital health citizenship, where individuals collectively author care practices, establish epistemic legitimacy, and forge therapeutic

strategies in the absence of state or clinical infrastructure. Cyberspace provides not only platforms for support but also serves as a laboratory for innovation and transformation.

Taken together, these findings suggest that people with ME/CFS inhabit a distinctive *digital habitus*, cultivated through repeated interaction, reflexivity, and resistance. Within this *habitus*, *suffering-capital* operates as a form of collective resource, legitimising authority and sustaining networks of care. The interplay between these forces exemplifies the community's complex navigation of the digital *pharmakon*. This synthesis underscores the need to interpret digital health citizenship not as an unambiguous good, but as a field of contested power, creativity, and survival.

However, the benefits of cyberspace are inseparable from its risks. The precariousness of patient authority, the variability in individual digital literacy, and the persistent circulation of pseudoscience all underscore the need for greater integration between community-driven insight and formal medical systems. Previous research in this area has not been consistent. When investigating online medical information seeking in Scotland, Moreland et al. (2015) found that online health information seeking by patients has been shown to affect medical consultations and patient-doctor relationships. Additional studies have shown that patients increasingly turn to the internet to prepare for doctors' consultations, discuss information they found online with their doctors, or complement, validate, and challenge the information provided by doctors (Caiata-Zufferey et al., 2010; Hu X et al., 2012). However, in more recent research, Wong et al. (2019) found a 'high prevalence of online health information seeking [led to] fewer respondents ask[ing] their doctors about the health information they found online' (p. 10). They suggested this was related to a lack of interest from doctors in patient-led investigations rather than patients being satisfied with their online research. This indicates that different populations with varying levels of media literacy are using the internet to inform their relationships with medical practitioners in diverse ways; some to enhance engagement and others to diminish it.

While those interviewed in this study revealed that online forums and knowledge banks were being used to present information to their doctors and the wider community, it must be noted that the participants had above-average levels of education, three of whom had science backgrounds, potentially inflating the prevalence of successful engagement between patients and practitioners. Overall, these findings suggest future research, policy, and clinical engagement must recognise the value of lived experience while safeguarding

against the systemic vulnerabilities that continue to shape the lives of those with ME/CFS. By adopting a collaborative and critically aware approach, we can provide more ethical, effective, and inclusive care for ME/CFS.

In conclusion, the ME/CFS community's engagement with cyberspace reveals a distinctive interplay between *habitus*, *suffering-capital*, and the *pharmakon*. Embodied practices of care are mediated through platforms that convert pain into knowledge, yet also risk commodifying vulnerability. Understanding this relationship offers a framework for rethinking digital health citizenship as a space of both emancipation and exposure, offering a reminder that the same technologies that heal can also harm.

CHAPTER 5: FINDINGS AND DISCUSSION, PART 2, EVIDENCE OF A POLITICAL-BIOSOCIAL HABITUS

Introduction

This chapter builds on the last discussion of how people with ME/CFS use cyberspace to help develop treatment protocols and examines how they build and sustain patient-led epistemic infrastructures online. It evaluates how collective practices, such as curating databases, co-reading medical literature, codifying terminology, coordinating visual campaigns, and sustaining influencer labour, convert *suffering capital* into epistemic and symbolic capital. I argue that these activities cohere into a *political–biosocial habitus*: a set of shared digital dispositions that redistributes authority over what counts as credible knowledge and legitimate representation.

The analysis proceeds in three stages. First, it traces infrastructures of patient knowledge (e.g., MEpedia, charity blogs, and research partnerships like DecodeME) that blend experiential testimony with biomedical evidence to establish trusted reference points. Second, it explores linguistic sovereignty and visual authorship, showing how terminology policing, community lexicons, and counter-stock-imagery collectively resist stigma and reframe public understandings of the illness. Third, it analyses influencer labour, both clinical and patient, to show how authority is maintained as infrastructure (moderation, documentation, training), rather than as spectacle.

This chapter makes three contributions to knowledge. First, it theorises a *political–biosocial habitus* for ME/CFS, showing how digital routines convert suffering capital into epistemic and symbolic capital. Second, it demonstrates how this habitus actively repositions patients within the field of health knowledge, reworking who is authorised to define credible evidence and representation. Third, it specifies the infrastructural mechanisms (databases, lexicons, image banks, and influencer labour) through which power is redistributed in practice, while also identifying the pharmakon risks of bottlenecks, gatekeeping, and burnout.

Throughout the chapter, the *pharmakon* logic of cyberspace is foregrounded: the same affordances that enable care, scrutiny, and coordination can also generate gatekeeping, burnout, and epistemic bottlenecks. This sets the stage for Chapter 6, which follows the

community as it confronts macro-institutions such as the welfare state, media, and policy, where fluctuating disability must be translated into bureaucratic legibility, and where the social model’s limits for energy-limiting conditions become most acute.

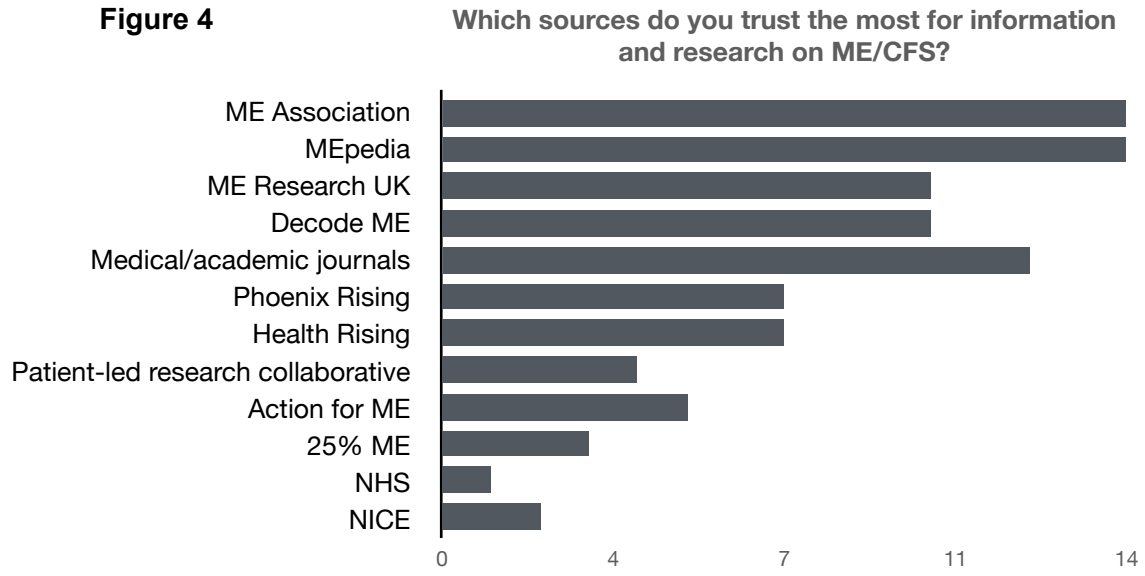
Infrastructures of Patient Knowledge: Information Databases

Patient-led Archives and the Politics of Trust

Research by Vainauskienė and Žemaitaitienė (2023) underscores the dynamics of knowledge sharing in chronically ill patient-led online health communities, where members actively disseminate information while seeking support. Their findings indicate that by nurturing mutual relationships built on trust and shared experiences, patients can enhance their collective knowledge and reinforce their identity as part of a community focused on overcoming the burdens inherent to their illness. The efforts of individuals with ME/CFS to create and maintain knowledge databases about their illness have become a crucial component of patient-led research and advocacy. The pursuit of knowledge building among ME/CFS patients illuminates a grassroots approach to addressing the challenges posed by a disease often fraught with misunderstanding and stigma. Findings in this section will highlight how the establishment of online information databases is central to the ability of ME/CFS patients to share knowledge, as these virtual spaces facilitate the exchange of experiences, insights, and research findings, which are particularly vital given mainstream medical institutions' often limited recognition of ME/CFS.

When participants were asked to reflect in their journals on the sources they trusted most for information and research about ME/CFS, their responses revealed a clear pattern (see Figure 4). The most frequently cited sources were those grounded in patient experience or directly involving patient contributions. The ME Association and MEpedia ranked first, each mentioned by 14 participants. This was followed by ME Research UK (10 mentions), DecodeME (10), and direct access to academic journals (12). Other trusted sources included Health Rising and Phoenix Rising (7 each), Action for M.E. (5), the Patient-Led Research Collaborative (4), and the 25% ME Group (3). In stark contrast, only two participants referenced NICE, and only one listed the NHS website as a source of reliable information.

Figure 4



These findings were further supported by netnographic observations, which showed that nearly all charities, research initiatives, and informational platforms (except the NHS website) were frequently shared and discussed in ME/CFS online communities. Notably, these often cited organisations and platforms have patient input at the core of their operations. This underscores the critical role of putting patients at the centre of discussions about their own health when building and maintaining trust within the ME/CFS community.

In Bourdieusian terms, these practices re-map the field of health knowledge. As patients accumulate epistemic and symbolic capital in spaces they control, they then re-import that capital into encounters with clinicians, charities, and media. These findings reflect a broader trend in health research that recognises patients as essential stakeholders. Initiatives such as the James Lind Alliance (JLA) were established precisely to ensure that patients, caregivers, and clinicians collaboratively determine research priorities (Nixon et al., 2020). Evidence consistently shows that involving patients in the research process increases both the relevance and the uptake of research findings (MacFarlane et al., 2016; Staley et al., 2020). When patients see their concerns and experiences reflected in research design, they are more likely to feel invested in and trust the outcomes.

This is evident in the trust participants placed in these patient-led efforts to collaboratively produce research. Such trust appeared deeply tied to the belief that these organisations not only understand but actively reflect patient needs and realities. As Chapman et al.

(2018) argue, patient trust in charities is significantly higher when the charity visibly incorporates patient voices and aligns its goals with community needs. The trust all participants reported holding for the ME Association was evidenced by their approval of the charity's continuous engagement with the community, both in pooling data and experience and in processing this information and disseminating it back to the community in clear, easily understandable ways. Five of the participants also referenced the ME Association's role as a lobbyist for their interests, which, again, they found to be a characteristic of the organisation that reinforced their trust. All participants during the interview stage also mentioned at least one of the organisation's staff, by name, demonstrating a human relationship with the organisation.

Conversely, trust in institutional sources like the NHS was almost entirely absent. Only one participant initially cited the NHS website as a resource in their journal; however, during the interview process, others reported that it had not been helpful to them. Interviews with other participants revealed a strong sentiment of mistrust or rejection. Participant M remarked bluntly, 'Why would I use that? There is nothing there, it's basically empty.' Participant D went further, stating, 'For us, the NHS website is a source of misinformation.' Perhaps most concerning was the experience of Participant K, who recalled,

> I actually did use it when I was first diagnosed, and they were advocating GET. So when I was offered GET […] despite seeing that patients weren't, like, behind it, I did it anyway, and it made me go from mild onset to moderate within a week, and I have never come back from that. […] So no. The NHS doesn't know what it's talking about.

These accounts reveal the consequences of disregarding patient voices in healthcare policy and information dissemination. When authoritative institutions like the NHS continue to promote outdated or discredited approaches, such as GET, despite widespread opposition from the patient community, they risk not only eroding trust but also causing real harm. In contrast, the organisations most valued by participants were those where patients are collaborators, not just subjects.

The ME/CFS community's clear preference for patient-led and patient-informed platforms illustrates the relationship between trust and inclusion. Participants' commitment to these ME/CFS organisations and their online platforms demonstrated that they viewed research that is transparent, participatory, and shaped by those with lived experience as producing more relevant outcomes. This was further evidenced by disclosures such as, 'If I hear

about anything new, such as treatment or whatever […] I always go straight to the ME Association to see if they have written about it, and if they have, I may consider it, but if they haven't, I won't' (Participant D). Another participant shared, 'If there's research published and [the ME Association] haven't reviewed it within a few weeks of it coming out, it's probably not worth reviewing because they will look at everything that's out there' (Participant K).

From Suffering Capital to Epistemic Capital

MEpedia was an online community-sourced database that all the participants referenced personal engagement with. The primary goal of MEpedia is to provide accessible, curated information that reflects the lived experiences of patients with ME/CFS. Much like Wikipedia, MEpedia allows users to log in and add information, update existing information, and link to external resources. The project includes information such as the latest reporting of ME/CFS in the news, the latest medical research, a directory of doctors in the UK that are recommended as allies for treatment, comorbidities with the illness and research papers on those, and a directory of treatment protocols that the community endorses, as well as those they do not. It also hosts detailed information packages about the illness, which can be downloaded and syndicated. These include primers for doctors, researchers, friends, family and care providers, journalists, patients, and the public. There are also pages for controversial characters in the ME/CFS community, lists of famous people with ME/CFS, detailed reports on the various multisystemic components of the illness, and lists of language and terminologies bespoke to the illness, to name only a small selection of the topics covered on the website. By utilising the collective knowledge of both patients and health professionals, MEpedia serves as a resource for disseminating vital information about the condition. A study by Vyas et al. (2022) discusses how patient participation in research and knowledge databases can improve the quality of life for individuals with ME/CFS and their families. Their findings underscore the need for platforms like MEpedia that integrate patient experiences and perspectives.

Interviewed participants reported that they used MEpedia predominantly as a reference tool for journal articles and the latest research, and four participants reported that they contributed to the site, two of whom added directly to the language section (which will be addressed later in this discussion). What makes MEpedia so unusual and interesting among medical wikis is its expansive, multidisciplinary scope. Unlike typical wikis that focus narrowly on aetiology, diagnosis, and treatment, MEpedia explores the sociopolitical,

linguistic, and historical dimensions of ME/CFS. It includes resources rarely found in standard medical references, such as detailed breakdowns of terminology debates, profiles of both pioneering and controversial doctors, curated primers for journalists and clinicians, and in-depth analyses of comorbid conditions. This broader lens reflects the complexity of ME/CFS and the contested nature of its recognition and treatment, making MEpedia not just a medical resource but a living archive of a patient-driven movement. Across these practices, *suffering capital*, the credibility accrued through lived hardship, visibility and *habitus*, becomes epistemic capital as testimonies are distilled into MEpedia entries, charity briefs, and research priorities. In Bourdieu's terms, the field of medical knowledge is gently but materially reconfigured when patient-authored archives become the default point of reference for patients and, increasingly, for clinicians.

Collaborative Reading and Epistemic Labour: Engaging with Medical Literature Online

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Barriers to Access and Health Literacy

The ability of individuals with ill health to read and understand medical literature about their illness is a critical aspect of health literacy. Jargon and complex terminology in medical literature pose significant obstacles for individuals with ill health. Many patients report difficulties navigating the dense language of medical journals, a challenge discussed in multiple studies (Korshakova et al., 2022; Hassan et al., 2019). Health literacy encompasses not only the ability to read and process information but also the ability to understand medical terminology and concepts (Deegan et al., 2020). Because 12 participants reported gathering information directly from peer-reviewed journals, they were asked to elaborate on this process.

Understanding medical journals requires an intersection of medical knowledge and health literacy skills. However, due to the impaired cognitive functioning experienced by this community, additional challenges such as maintaining focus, processing new information, and tolerating light or sound (which could impact both textual reading and audio narration) can affect how this community understands and processes complex information. Of the 12 participants who declared using journal literature to inform their understanding, all emphasised the importance of using peer-reviewed knowledge in accordance with community information. Four participants particularly noted that reading journal articles' methodologies is as important as evaluating results, because methodological practices can be flawed. Two participants directly referenced the flaws in the methodology of the PACE trial as a precedent for how flawed methodology could produce outcomes that might corrupt data accuracy.

During the interview process, some participants described how they approached research by isolating what they deemed the most valuable section of information. For example, one participant shared;

> So sometimes I'll use sites like the ME Association or MEpedia, other times, if I've looked into something like a Google search and an article comes up, I will read the abstract. Because that will give me whether or not the treatment was effective, or, you know, and then I tend to look at the participants, because sometimes they'll mention comorbidities and stuff like that. And then, like the conclusions and the

> results. I don't read the whole thing, you know, journal articles are like 20 or 30 pages long. I don't have it in me to read that much (Participant N).

And another relayed a similar lack of ability to focus on entire articles;

> I have a PhD in science, so I am used to reading a lot. So, peer-reviewed journal papers are things that matter to me. I can't read a paper anymore, and I can barely manage an abstract. My concentration is terrible. My memory's not very good, so if it interests me enough, I'll go to where I think the bit of interest within the paper will be (Participant C).

Other participants highlighted the importance of being critical in their evaluation and emphasised how, even though research may be peer-reviewed, that doesn't necessitate its accuracy.

> I try to be as academic about it as possible, and I wouldn't probably treat it any differently, you know, if I were evaluating a source for, you know, writing an essay or something, evaluating a source, and evaluating the research background. […] You know, what is the researcher's background? Who are you? You need to know who they are and why they are doing the research (Participant L).

Beyond evaluating the bias or lack of trust in certain researchers, others expressed a need to review methodologies, one expressed,

> As we know, with the brain, we can get fatigue and the general cognitive sort of malaise, and that's really tough now. […] My background is in psychology, and reading peer-reviewed research obviously helps. It's easy to sort of like, read the results and be like, OK, that's good. But when you read into how a study has been carried out. That's when you sort of start to realise maybe that, like that, the evidence isn't as great as we want it to be. Obviously, the PACE trial is such a good example of that because, obviously, like I think when the information initially came out, it showed that CBT and graded exercise therapy are great for ME. But then, if you look at it, they have changed the definitions of what ME recovery is. So it's very easy to make a study look like it says one thing, but you have to read it to really know what's going on, sort of like looking behind the curtains. (Participant J).

These expressions demonstrate a lack of trust in medical science and academia, despite all participants also presenting themselves as advocates for both.

Distributed Cognition and Collective Interpretation

Where these participants were demonstrating varied yet committed engagement with medical literature, all participants expressed the need for help in this area, and four participants described processes of collaborative reading. One shared,

> If I'm not able to read it myself, which for a long time I wasn't able to, but if I wanted to be up to date on what was happening, and also if there was anything like a therapy or supplement that I perhaps wanted to try [my carer would] literally read the journal article outloud for me, but if I'm very unwell, like the last couple of weeks, I have got someone who isnt ill to read some stuff for me and then they precis it for me with the highlights so that I know I'm up to date and know what's going on (Participant I).

And others shared similar processes where their carers would support with literature interpretation;

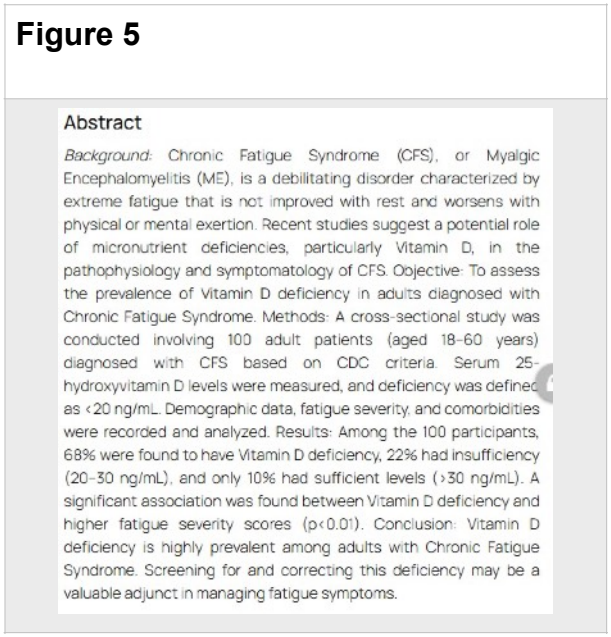
> My main port of call is the ME Association and I get my literature from their suggestions, and my mother is a member. […] She'd take books out from the library that she had researched online, and because I was quite young at the time [of diagnosis], you know, I didn't really fully understand, so she would evaluate them and share what she found (Participant L).

This practice of using community networks to evaluate medical journals was also evident in the netnographic process, which documented 57 instances of journal articles posted in ME/CFS Facebook forums. For newly published articles, the ME Association would often share them along with its own reviews and synopses. They disseminated them via their social media channels and published permanent blog posts on their website containing these details.

It was also observed that articles were shared directly by community members, and on these posts, it was common to see requests such as 'Does anyone have an easy read summary of this?', 'Can anyone explain this to me?', 'Is there a cheat sheet somewhere for this?' or questions like 'Has anyone reviewed the methodology?' or 'I can't seem to find the sample size for this?'. There was also evidence of restricted journals (i.e., not open access) being downloaded and syndicated. On three occasions, community members asked whether anyone had university library access to download specific journals for which they could not obtain full transcripts.

It was also noticed that sometimes, journal abstracts would be turned into a photographic post, so as to highlight the study, with links to the study shared below the post (see Figure 5), a way of utilising the medium to highlight the core research findings whilst facilitating a full read of the document to those who are able. These demonstrations of how this population evaluates peer-reviewed journals and medical data support prior findings that online platforms can enable individuals with chronic illnesses to collaborate and create content that clarifies medical concepts through the lens of lived experience (Mankoff et al., 2011). These collaborative learning processes can empower patients by allowing them to take charge of their health narratives and interpret medical information accurately within supportive online communities.

Figure 5



Abstract

Background: Chronic Fatigue Syndrome (CFS), or Myalgic Encephalomyelitis (ME), is a debilitating disorder characterized by extreme fatigue that is not improved with rest and worsens with physical or mental exertion. Recent studies suggest a potential role of micronutrient deficiencies, particularly Vitamin D, in the pathophysiology and symptomatology of CFS. Objective: To assess the prevalence of Vitamin D deficiency in adults diagnosed with Chronic Fatigue Syndrome. Methods: A cross-sectional study was conducted involving 100 adult patients (aged 18–60 years) diagnosed with CFS based on CDC criteria. Serum 25-hydroxyvitamin D levels were measured, and deficiency was defined as <20 ng/mL. Demographic data, fatigue severity, and comorbidities were recorded and analyzed. Results: Among the 100 participants, 68% were found to have Vitamin D deficiency, 22% had insufficiency (20–30 ng/mL), and only 10% had sufficient levels (>30 ng/mL). A significant association was found between Vitamin D deficiency and higher fatigue severity scores ($p < 0.01$). Conclusion: Vitamin D deficiency is highly prevalent among adults with Chronic Fatigue Syndrome. Screening for and correcting this deficiency may be a valuable adjunct in managing fatigue symptoms.

These findings also demonstrate that knowledge sharing among ME/CFS patients often depends on social factors and media literacy. This emphasis on comprehension and perceived value also resonates with approaches to media and medical literacy that foreground disabled people as active producers of knowledge rather than passive recipients of information. Such principles are reflected in the practices promoted by the *British Journal of Learning Disabilities*, which advocate accessible communication and ask researchers to produce “easy read” summaries as a means of supporting participation, authorship, and epistemic agency among people navigating complex health information (British Journal of Learning Disabilities, 2025).

Research on the intention to share knowledge in online communities highlights the role of self-efficacy, defined as the confidence individuals have in their ability to share information effectively and to understand complex medical content (Alajmi, 2012). In the context of ME/CFS, this reflects how patients' shared understanding of their illness can positively influence their willingness to contribute to collective knowledge bases. Consistent findings by Cheung et al. (2013) identify user satisfaction as a critical factor in the ongoing contribution of knowledge within online communities, emphasising that perceived value and positive feedback are vital for sustaining engagement.

When discussing the utilisation of these types of information databases by patients with ME/CFS, the work by Kim et al. (2020) highlights the importance of integrating patient-reported outcomes into clinical research via these databases to build and sustain trust. Their findings underscore the value of understanding the patient's perspective in assessing treatment efficacy, marking a shift towards a more patient-centred approach to ME/CFS research. The researchers argue that databases that prioritise patient-reported outcomes metrics are vital in capturing the multifaceted nature of ME/CFS, as symptoms extend beyond mere fatigue to cognitive dysfunction, pain, and autonomic dysregulation.

The findings in this thesis align with Kim et al. (2020), highlighting that this community is mobilised for collaboration, albeit they may lack institutional partners who recognise the value of their data. The findings indicate that these databases are of immense significance to the community, as reflected in their rigorous review and sharing practices. The evolution of knowledge-sharing practices among ME/CFS patients suggests a path towards improved health outcomes through data aggregation and collaboration. As shared experiences enrich the understanding of ME/CFS, patients shift from passive subjects to active participants in medical discourse, driving research priorities from the ground up.

This shift aligns with previous research on identity-driven communities that emphasises community identity's role in promoting knowledge sharing (Hsu et al., 2012). These collaborative literacies illustrate an attentional practice that is at once protective and productive as patients conserve scarce cognitive energy by distributing reading and relying on trusted "easy-read" summaries, while still raising the evidentiary bar for claims. This is the *pharmakon* in action, the same platforms that can accelerate superficial uptake also enable peer scrutiny that filters low-quality evidence and amplifies methodologically sound work. In theoretical terms, these collaborative literacies function as a distributed form of

cognition and care. They externalise cognitive labour through summary writing, carer reading, and communal annotation, illustrating how digital networks can compensate for the embodied constraints of chronic illness while producing collective expertise.

Biobanks and Biomedical Collaboration: Mobilising Participation Through Trust

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Patient-Centred Design and Participation

As discussed in the earlier chapters, the understanding and management of ME/CFS have long been impeded by the disease's heterogeneous presentation and the challenges associated with its diagnosis and treatment. Recent advancements in biomedical research necessitate the establishment of comprehensive biobanks that not only facilitate research into this condition but also aid in the development of effective intervention strategies. Although mentioned by only two of the interviewed participants, who described it as 'promising' and 'potentially very important', one prominent initiative in this area is the EUROMENE project, which aims to establish a wide-ranging database of biomarkers across Europe for ME/CFS patients. The project represents a collaborative effort to collect biomarker data to correlate clinical profiles with biological findings. According to Scheibenbogen et al. (2017), the EUROMENE project aims to enhance diagnostic sensitivity and specificity, which are fundamental to developing surrogate markers for clinical use in ME/CFS and guiding future therapeutic interventions. The initiative emphasises the necessity of multinational cooperation to build a research framework that transcends geographical and institutional boundaries to better understand ME/CFS. However, the DecodeME project received more robust recognition.

The DecodeME study is the largest genetic research initiative ever undertaken to investigate ME/CFS. It aims to uncover potential genetic causes of the illness by analysing DNA samples and extensive health surveys from over 10,000 individuals with ME/CFS. This patient-centred approach is designed to improve scientific understanding and ensure that the voices and experiences of people with ME/CFS shape the research at every level. As stated by the project itself, 'People with ME/CFS are at the heart of the ME/CFS Biomedical Partnership and are involved in all aspects of the research' (DecodeME, n.d.). This collaborative foundation has been central to the study’s success in engaging the ME/CFS community. All participants interviewed for this research were aware of the DecodeME project and had taken part in it. Importantly, all respondents reported learning about the study via social media, especially Facebook forums and Instagram posts, or through links shared within their community.

Not only did they enrol, but they also actively promoted the project. One participant noted, 'Well, this is something we all should be doing. I made sure I told everyone I know with ME about it' (Participant E). Another added, 'I shared the hell out of this while they were recruiting for it' (Participant F), while Participant G explained, 'Everyone is behind this, all the organisations that are working for us, so we have to be hopeful and we have to do our bit.' This demonstrates how social media networks acted as vital conduits for the project, creating a sense of collective action and shared purpose. Participants praised the study's accessibility, particularly its ease of participation. The process was deliberately designed to accommodate the unique needs of people with ME/CFS, many of whom are housebound or have limited energy. One participant shared, 'It was just a couple of clicks, fill in the form, then they posted the kit out to you. So I did that at home, and then my friend posted it back the same day, it couldn't really have been easier' (Participant K). Another echoed this sentiment, saying, 'It was simple, wasn't it? I actually didn't get my kit. I don't know why, but they just sent another one straight away. […] It wasn't an invasive process, really easy' (Participant C). Another added, 'Well, it was so accessible. They knew, like we do, most of us don't get out much, so they delivered to us, and with the surveys, they were online, and you could go back to them and complete them in parts if you had a crash. […] During the whole process, you could tell they knew about our struggles' (Participant L). These accounts suggest that the DecodeME team's attention to accessibility and responsiveness further fostered trust and enthusiasm for the project. Accessibility here is not only about ethics, but also about capital formation, as lowering barriers to participation expands the volume and diversity of data, strengthening patients' position in the biomedical field.

DecodeME's design involves collecting DNA samples alongside detailed survey data on symptoms, health history, and lifestyle factors. This allows researchers to link genetic findings with patient experiences using qualitative and quantitative methods. Additionally, whole-genome sequencing is used to detect variants potentially linked to ME/CFS (Shepherd, 2021). Unlike prior studies with smaller sample sizes, DecodeME's large sample size and integrated methodology significantly expand the potential for meaningful discoveries. The project's partnership with ME/CFS charities and patient groups has also helped ensure that the research remains grounded in the real-world concerns of the community it serves. DecodeME's commitment to transparency and ongoing communication has also played a major role in sustaining community involvement. The team shares updates regularly via blogs, social media posts, and webinars, such as those

hosted on YouTube, which present findings and progress in accessible language (DecodeME, 2023).

This level of engagement has helped participants feel connected to the research and valued in the process. Four participants volunteered that they had been watching the webinars and found them engaging and positive. What was primarily evident from these findings was that participants not only trusted the project and found it to galvanise camaraderie, but some participants also expressed sincere hope for what it might achieve. 'I'm hopeful that this may actually start to bring in some results because it's a proper large amount of data they have on us now', (Participant K) said one participant. Another expressed deeper optimism: 'I feel like this has to be the way, you know, how we make a breakthrough. If we make a breakthrough, and we must, it's going to be through something like this' (Participant A).

Gatekeeping and Fragile Infrastructures

Although all interviewed participants were also aware of the UK ME/CFS Biobank, none had contributed their data to that project. Despite this lack of direct involvement, they generally expressed trust in the project and a willingness to participate. One respondent remarked, 'Well it's small, isn't it, but you know, they are doing it properly' (Participant M), another shared, 'the ME Association are running that aren't they so its definitely something we should all be interested in' (Participant B), while another stated, 'I would happily have donated however I didn't know how' (Participant L), a sentiment echoed by four others. This reveals a contrast between trust in the biobank and limited practical knowledge about it. Several participants noted their uncertainty about the biobank's impact through comments such as 'I'm not really sure what they have achieved' (Participant E). Such gaps in awareness may be partly due to the biobank's recruitment strategy, which relied on general practitioners and specialists from ME/CFS clinics to identify and invite participants. This approach effectively placed medical professionals as gatekeepers, potentially excluding the many individuals with ME/CFS who are without active clinical engagement.

Additionally, for a population often housebound or bedbound and living with complex access needs, participation requirements, such as travelling to medical centres for blood, urine, and tissue sampling, could pose significant barriers. The UK ME/CFS Biobank holds such samples from approximately 600 individuals, including those with varying degrees of ME/CFS severity, healthy controls, and individuals with similar symptoms but different

diagnoses. These high-quality, anonymised samples are linked to rich clinical datasets and have been shared with research teams across Europe (Lacerda et al., 2018). Although largely patient-led, the biobank was established with funding from the ME Association, ME Research UK, and Action for ME, yet it still relied on clinical infrastructure for participant access (Lacerda et al., 2018). This may explain why some individuals, despite being part of the ME/CFS community and expressing support for the initiative, were not fully familiar with its operations. While this biobank is grounded in patient advocacy, structural and logistical barriers, such as gatekeeping and access requirements, may have limited broader engagement among those it was intended to serve, and it highlights the importance of cyberspace in enabling this community to mobilise to participate in research.

The clear mandate of these biobanks is to foster international collaboration. Studies examining biobanking efforts in ME/CFS highlight that global-scale data collection can facilitate larger sample sizes and the inclusion of diverse populations. Yang et al. (2022) and Xue et al. (2021) discuss the importance of international cooperation for establishing treatment protocols, arguing that data from treatment modalities that are most common in Asia, such as acupuncture and moxibustion, should be included in research databases focused on ME/CFS. Such diverse methodologies enrich the data landscape, allowing for comprehensive analysis and understanding of healthcare outcomes. It can be argued that cyberspace has facilitated international cooperation in this area, as projects and initiatives can be disseminated via social media, thereby raising awareness of both calls to participate in biomedical data sharing and the outputs of such projects.

However, they remain fragile in the face of political ideologies. Indeed, while writing up these findings, it was reported that Columbia University will lose $ 400 million in federal funding due to its rejection of the new ideological restrictions on academic practice imposed by the current U.S. government. For the past seven years, Columbia University has housed the USA's largest biomedical research centre dedicated to ME/CFS. It is currently engaged in three longitudinal research projects, one of which is a collaboration with the University of Edinburgh in the UK. Researchers have now announced that their budget has been removed entirely, and these projects are unlikely to continue (Cueto, 2025). This event demonstrates how fields of power (state policy, university governance, funders) define the boundaries of what the ME/CFS *habitus* can develop. Therefore, durability depends on linking patient archives to institutional repositories under shared governance, to safeguard epistemic capital and to democratise access.

This biopolitical event highlights the structural influence of fields on *habitus* and the resulting challenges of power faced by scientists, academics, and the patient community, in which funding for this illness remains both fragile and extremely low relative to the financing for other comparable chronic health conditions. It also reveals the necessity of this patient community's drive to maintain consistent, robust archives of their own, as data held by academics or organisations could be lost due to financial uncertainty or political fluctuations.

This dependency also highlights the infrastructural politics of data stewardship when patient-authored archives coexist with institutional repositories, and durability depends on open standards, mirrored storage, and shared governance to prevent epistemic loss. DecodeME demonstrates how a *political–biosocial habitus* operates. Here we can see how patient-led mobilisation lowers barriers to participation, and co-designed infrastructures convert dispersed suffering into analysable data. Yet it is important to highlight that this ecosystem is fragile; for example, funding can be volatile for patient-led operations, and platform dependencies can be restricting. To this end, there is a risk of producing epistemic bottlenecks. Sustaining these gains, therefore, requires durable links between patient archives and institutional repositories to mitigate these risks. If databases stabilise what counts as evidence, terminology stabilises who the evidence is about. I turn now to the linguistic market in which legitimacy is named, contested, and enforced.

Linguistic Sovereignty and Terminology Control

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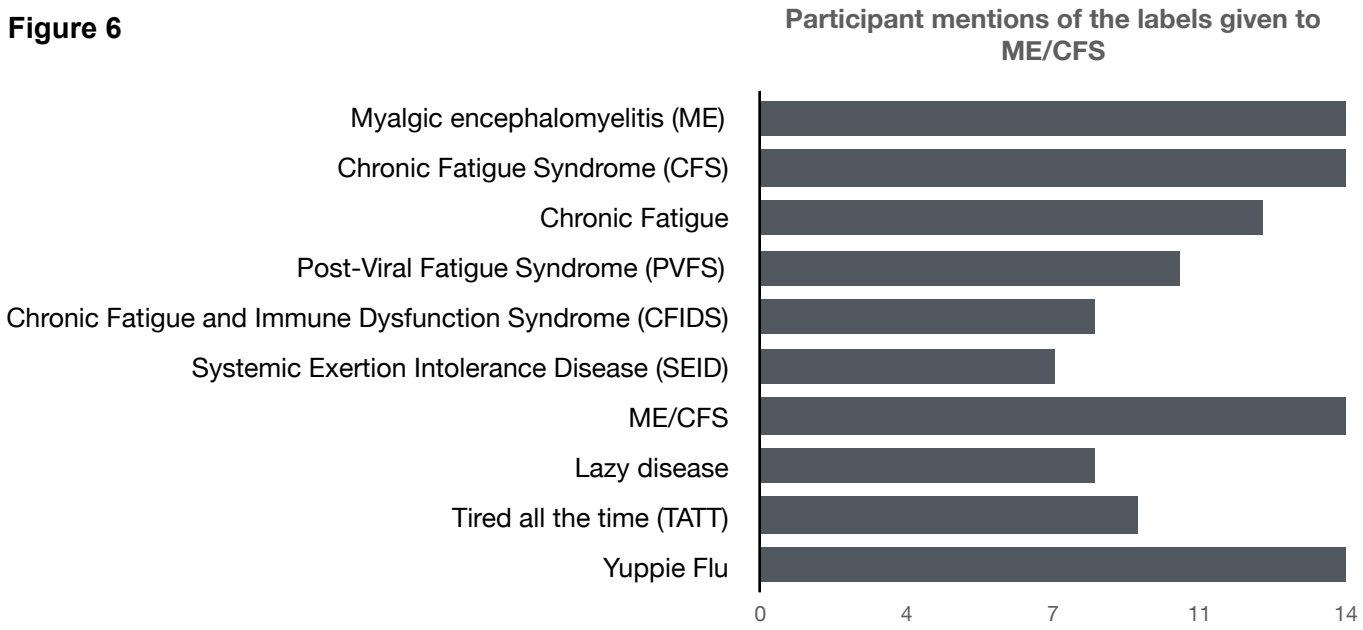
Reclaiming and Policing Terminology

In this section, language is examined as both the medium and the product of a *political–biosocial habitus*. The following discussion advances Bourdieu's (1992) concept of *habitus* by showing how linguistic control becomes a mechanism through which marginalised groups resist externally imposed classifications. Where I have previously detailed that Bourdieu emphasised how language tends to reproduce domination through distinctions and symbolic capital, the ME/CFS community demonstrates how the collective authorship of language can redistribute authority. This analysis builds on Bourdieu's conception of linguistic capital but extends it through Fricker's (2007) notion of *epistemic injustice*, specifically, how testimonial credibility is unevenly distributed, and through Bowker and Star's (2000) work on classification as itself a form of infrastructure.

The ME/CFS lexicon demonstrates how patient communities re-engineer classification systems to repair hermeneutical gaps left by institutional discourse. Through digital collaboration, terminology policing, and community lexicons such as MEpedia, participants construct a counter-linguistic economy that redefines legitimacy on their own terms. In doing so, they enact a form of reflexive-*habitus* that challenges the hierarchical labelling historically attached to their condition. Language is central to *habitus* because it is both a product of *habitus* and a medium through which the structures of *habitus* are formed, expressed, and reinforced. Saussure (1959) described language as 'all the linguistic habits which allow a subject to understand and make itself understood' (p. 75). Within this notion, language is part of the mechanisms for structuring and reinforcing both *habitus* and identity. Through both the netnographic process and interviews, the importance of crip authorship, the active patient ownership of language and terminologies (Hickman, 2023), was revealed. This was evidenced by an apparent, concerted effort by the community to control language specific to ME/CFS, and by their collaborative practices to mechanise this.

One point raised through interviews and reflected in online forums was the perceived damage caused by the language used to label the illness. Over the years, the name assigned to the illness has been revised or completely changed. In Figure 6, you can see the various labels assigned to the illness and participants' familiarity with them.

Figure 6



Where labels such as ME/CFS, CF, CFS, ME, PVFS, CFIDS, and SEID attempt to provide descriptive medical definitions of what doctors believed to be either underlying causes of the illness or overarching symptoms, participants articulated that this has contributed to both confusion about the illness and its legitimacy. Two participants shared, for example, that 'CF isn't even the same illness […] it is its own thing' (Participant E) and that 'CF is a symptom of the illness yet for three years that's what they wrote on my medical records […] completely undermining that I had an actual illness' (Participant M). Other labels, such as TATT, Lazy Disease, and Yuppie flu, were clearly derogatory in language. One participant shared, 'I find them all disgusting. People sometimes think it's not an illness, it's just laziness, or an affliction for women, something in the mind, not the body' (Participant A). Additional phrases they found offensive included 'wastebucket diagnoses', a term suggesting that ME/CFS is a catch-all for unexplained symptoms, implying a lack of legitimacy. They also referenced language such as 'malingering' or 'secondary gain', which connotes accusations that patients are faking illness for benefits, a view historically embedded in some of their reported occupational health assessments, which they found offensive and minimising of their suffering. All participants provided a consensus that these phrases were 'derogatory and wholly inaccurate' (Participant D).

These findings align closely with classical and contemporary theories of stigma. Goffman (1963) defines stigma as an attribute that is deeply discrediting, transforming an individual,

‘from a whole and usual person to a tainted, discounted one’ (p. 3). The derogatory and trivialising labels applied to ME/CFS, such as “yuppie flu” or “lazy disease”, operate precisely in this way, marking patients as morally suspect rather than medically unwell. Subsequent work by Link and Phelan (2001) conceptualises stigma as a social process involving labelling, stereotyping, separation, and status loss, all enacted within contexts of unequal power. The persistence of negative labels for ME/CFS demonstrates this process in practice, where institutional and cultural forces have sustained a hierarchy between “credible” and “non-credible” illnesses. Parker and Aggleton (2003) similarly argue that stigma functions to reproduce existing power relations, casting some identities as legitimate while delegitimising others. The language participants describe, therefore, reflects more than misunderstanding. It is a mechanism through which symbolic power operates to maintain social boundaries between health and illness and between productivity and dependency.

What was also revealed during the interview process was that not all participants agreed on the label that should be used to describe their illness. One participant shared that,

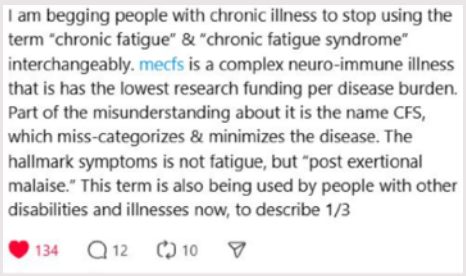
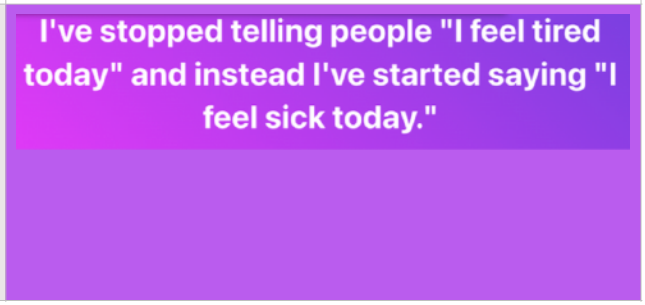
> The name M.E. does not bother me either way; the full title can be a bit of a mouthful and difficult to spell, but medical things tend to be that way. On the other hand, the term Chronic Fatigue Syndrome does put focus on only one aspect of the illness, which tends to trivialise it in some people’s minds, as they then think that it is just about feeling tired, which most people experience in day-to-day life, so they do not see it as a 'proper' illness. For that reason, when talking to other people about it, I either refer to the illness as M.E. or as a neurological condition (Participant L).

Others were more forthright about what they do and don’t like, for example:

> I don't like CFS, I think it's unhelpful as it suggests fatigue is the only/main issue. CFS also has an unpleasant history. CFIDS is a slight improvement as it mentions the immune system. I like that SEID includes the word disease rather than syndrome (Participant H).

Despite this, all participants agreed that they generally use and prefer the term ME; however, four participants mentioned that they usually end up using the term ME/CFS because it is more inclusive for individuals who have an original diagnosis of CFS on their medical records. One said, 'It’s better to use ME/CFS with doctors because if you say ME, sometimes they don’t know what you are talking about […] they often don’t know it’s the same thing' (Participant G).

This was also a contentious issue in forums. In forums, where on occasion a community member would refer to the illness as 'CFS,' the term most patients in the UK have on their medical records, this was often met with comments such as 'Can we at least call it ME/CFS' or 'when you say CFS, you undermine our condition' or 'this is an ME forum, please at least in here, let's call it what it is.' While some of these comments may be received as aggressive, they were typically met with responses such as 'thank you, I didn't know' or 'that's really interesting, thanks for sharing'. As shown in Figures 7 and 8, requests for the use of certain terminology were usually accompanied by explanations and rationales, or by demonstrations of how they employed the expressions. What this did demonstrate, however, was clear evidence of gatekeeping language and terminology.

Figure 7	**Figure 8**
	

This gatekeeping activity can also be interpreted through the lens of boundary work, a concept articulated initially by Gieryn (1983) to describe how scientific communities demarcate legitimate knowledge from non-science. In digital contexts, scholars such as Lingel (2017) explore how online groups negotiate membership, identity, and epistemic authority through communal practices of inclusion and exclusion. What emerges in these ME/CFS forums is a form of digital boundary work, in which the policing of language, such as the preference for "ME" over "CFS," serves to delineate community identity and protect collective epistemic legitimacy. Yet, as with all boundary work, these linguistic protections can risk exclusion, particularly for newcomers, carers, or non-English speakers unfamiliar with preferred terminology, revealing the ongoing negotiation between solidarity and openness within the *habitus*. By asserting control over terminology, participants construct a shared linguistic *habitus* that resists external misrepresentation and reinforces insider expertise. Here, terminology policing also constitutes a form of market intervention in the linguistic field. By setting the price of misnomers, e.g. "CFS" as reputationally costly, the community revalues preferred labels, e.g. "ME or ME/CFS", and raises barriers to delegitimising speech.

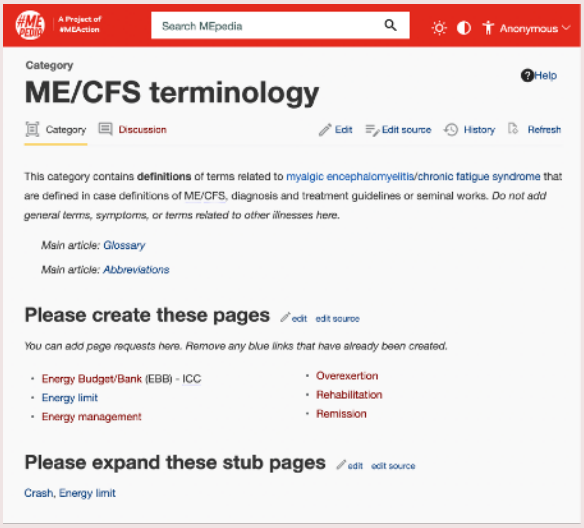
Crip Authorship and Community Lexicons

There was further evidence of “crip authorship”, such as that referenced in chapter 3, and the reclamation and creation of language by disabled people to describe their own experiences, in the rich terminology used by patients to discuss their symptoms. These terms were prevalent across both online forums and interviews, with several occurring more than 30 times. Phrases like post-exertional malaise (PEM) (also referred to as a 'crash' or 'relapse') and ‘brain fog’ provided nuanced ways to articulate hallmark symptoms such as cognitive dysfunction and energy collapse. Metaphors like the ‘energy envelope’ helped describe the limited and variable nature of energy availability, while ‘wired but tired’ captured the paradox of exhaustion combined with an inability to rest. Others, such as ‘payback’, ‘crushing limbs’, and ‘the wall’, gave visceral form to the physical heaviness and unpredictable crashes that define the illness. More expressive terms like ‘PEM hangover’, ‘zombie mode’, ‘sensory hell’, and ‘shutdown’ conveyed the overwhelming sensory and neurological dimensions of the condition.

These patient-generated expressions are far more than mere colloquialisms; they are crucial linguistic tools for validating, articulating, and sharing complex embodied experiences. In doing so, they challenge biomedical language that often lacks the vocabulary to fully capture chronic illness, while fostering solidarity and clearer communication within patient communities and with healthcare professionals alike. Further evidence of the organisation and protection of language and terminology is provided by MEpedia, which features a section dedicated to 'ME/CFS terminology.'

This section includes languages and terms commonly used within the community. In Figure 9, one of these pages displays requests for community contributions, such as 'Please create these pages,' followed by a list of terms, including energy budget/bank, energy limit, and others. Messages also encourage patients to 'please expand these stub pages.' This illustrates the community’s commitment to safeguarding and compiling terminology, while also highlighting the depoliticised nature of the process, as these glossaries are crowdsourced, updated, and maintained by patients.

Figure 9



The importance of addressing linguistic misrepresentations of people with ME/CFS in the media has been underscored by a pivotal study conducted by Murray et al. (2019), (previously mentioned in Chapter 1). Their research explored how the media's representation of ME/CFS can reinforce misconceptions and stigma towards the condition and its patients. A central discovery of their study is the differing narratives surrounding male and female patients. The researchers observed that women are often portrayed in supportive narratives that highlight their vulnerability and lack of agency. They use the phrase 'duvet woman' metaphorically to describe these portrayals, which stress submission to their illness and align with societal feminine expectations of emotionality and fragility. In stark contrast, they found men with ME/CFS are often represented as 'action men,' connoting strength, resilience, and the capacity to conquer challenges (Murray et al., 2019). These masculine narratives promote ideals of stoicism and independence, often suggesting that illness should not interfere with a man's productivity or value. The authors contend that such representations can lead to insufficient treatment and support for patients, thereby exacerbating their suffering. This relays the vital need for accurate and compassionate representations that truly reflect the experiences of individuals living with chronic health conditions. Findings from this study demonstrated community agreement with Murray et al.'s (2019) findings and provided evidence of an active community, driven to depoliticise their suffering through collaborative, community-led control of their narratives.

Institutional Resistance and the Politics of Naming

A discussion with one participant offered a compelling illustration of the political significance of language in the context of ME/CFS and the tensions that arise when patients seek to assert their epistemic authority. Participant M, who served on a patient advisory group for the UK government's The Interim Delivery Plan on ME/CFS (Department of Health and Social Care, 2023), described the official rhetoric of patient inclusion as contradictory to her lived experience of the process. Although the plan stated it would centre patient voices, she reflected that 'the whole process felt like a battle […] and to be honest, the plan is pretty non-committal […] which is really disappointing.' One particular 'battle' she recounted involved the inclusion of a language section within the report, an effort to document terminology that ME/CFS patients find harmful, dismissive, or invalidating. She recalled how 'oh the government were strongly against it […] they didn't see the point in it,' and that tensions escalated to the point where 'the different patient advisory groups were going to all pull their support for the document unless it was included.' Despite significant backing from medical professionals, she described how 'government representatives were very aggressive with us,' ultimately agreeing only to 'a redacted, shortened version that omitted some of the really important bits that would have been useful to doctors.' Yet, she concluded, 'Still, I am glad that it is in there.'

This account highlights the deeply contested nature of language in the politics of chronic illness. Resistance to including a language section reveals how institutional actors often underestimate or actively oppose patients' epistemic contributions, especially when those contributions challenge prevailing biomedical norms. The inclusion of the section, albeit in a diluted form, represents both a symbolic and a practical victory, asserting patients' right not only to be heard but also to shape the discourse through which their condition is understood. This story is important because it demonstrates that language is not merely descriptive but constitutive, as here you can see how it can directly shape policy, inform care, and ultimately affect whose realities are recognised as legitimate within healthcare systems.

When discussing language and symbolic power, Bourdieu (1992) refers to the 'labour of representation', which he defines as the labour people 'continually perform in order to impose their own vision of the world or the vision of their own position in the world' (p. 235). These findings demonstrate that this community strategically dedicates their resources to the labour of representation. The policing and codification of terminology are

also attention controls as they channel scarce interpretive labour toward shared meanings, reducing the cognitive costs of continual re-explanation to outsiders while asserting symbolic sovereignty.

Bourdieu (1984) suggests *habitus* is created and reproduced unconsciously, 'without any deliberate pursuit of coherence […] without any conscious concentration' (p. 170). However, these findings evidence a concerted effort by this population to mediate collective terminology and reinforce linguistic understandings, with what appears to be a direct motive to strengthen *habitus*. In this way, we can see that the affordances of cyberspace allow people with ME/CFS who, due to the distinct characteristics of their illness, would ordinarily be unable to maintain consistent interaction with others without these technologies, to take a measured and intentional approach to communication. Indeed, it may be precisely because of the limitations they experience in communication and the immense fatigue that communication can trigger for people with ME/CFS that this population has organised into a collective mandated to linguistic solidarity. These practices show that, in this community, *habitus* is consciously shaped rather than passively absorbed; a direct contrast to Bourdieu's idea of *habitus* as something acquired unconsciously through socialisation. In this way, the ME/CFS community's collaborative management of terminology exemplifies how online collectives undertake both stigma resistance and digital boundary work simultaneously.

By reclaiming and standardising the language used to describe their illness, participants not only mitigate the symbolic violence of stigma (Goffman, 1963; Link & Phelan, 2001) but also establish epistemic boundaries that safeguard community expertise (Lingel, 2015). These discursive practices demonstrate how people with ME/CFS use the affordances of digital space to transform stigmatised identities into cohesive, agentic publics capable of challenging biomedical and media narratives. These findings, therefore, show how linguistic authorship functions as a deliberate recalibration of the linguistic market rather than a passive adaptation to it. The community's co-production of terminology and its enforcement of linguistic norms transform symbolic power from a top-down mechanism of domination into a collective strategy of legitimacy. In this respect, the ME/CFS community not only reproduces *habitus* but actively remakes it, illustrating how digital affordances allow new forms of reflexive agency to emerge within fields historically governed by professional authority. This deliberate organisation of language also reflects the *pharmakon* logic discussed earlier. While empowering in its consolidation of meaning and

identity, it risks exclusionary effects through gatekeeping and the policing of linguistic boundaries. However, naming travels with seeing and the same struggle over terms reappears in images, where symbolic capital is won or lost in a single frame.

Visual Habitus: Images, Visibility, and Digital Witnessing

Counter-Imagery and Testimonial Photography

Visual culture represents another dimension through which the *political–biosocial habitus* of the ME/CFS community becomes both visible and sustained. Where language structures interpretation, imagery mediates recognition and visibility. This section explores how visual practices, ranging from curated photography to memes, extend the community's reflexive *habitus* into the visual realm. These practices appear in three main forms: (1) counter-stock imagery, which challenges trivialising depictions of illness; (2) testimonial witnessing, in which patients share personal photographs and images of suffering; and (3) memetic micro-narratives, humorous or affective fragments shared to build solidarity. This discussion explores how visibility is both cultivated and rationed within the community. It also reflects the *pharmakon* dynamic that runs throughout this thesis as visibility empowers through recognition but can also deplete through exposure.

Visual representation strongly influences how chronic illness is perceived publicly. Previous research shows that media imagery often associates illness with stigma and deviance, reinforcing negative stereotypes (Soffer & Ajzenstadt, 2010). In contrast, ME/CFS communities express frustration not at being depicted as "othered," but rather as "too well." During the netnographic process, fourteen conversations referenced the "Real ME" photo campaign, initiated by the ME Association in response to patient complaints about stock images portraying mild discomfort rather than serious illness (The ME Association, 2018). The campaign invited patients to submit authentic photographs depicting the realities of their condition. This practice of sharing images of suffering also enacted testimonial witnessing, a process of mutual recognition and validation. As Naef (2006) describes, 'bearing witness is being present and attentive to the truth of another's experiences' (p. 146). Such witnessing extends beyond clinical contexts into social and familial spheres, nurturing resilience through recognition. Nearchou et al. (2017) similarly emphasise that acknowledgement of a child's chronic illness within the family promotes understanding and coping. These insights illuminate how witnessing functions within the ME/CFS visual habitus as a communal, relational act that extends care beyond the self and sustains the collective identity of the group.

Figure 10: **Photocredit (weiblich): Reinhard Balzer / Deutsche Gesellschaft für ME/ CFS**	**Figure 11:** **Photocredit (männlich): Lea Aring / Deutsche Gesellschaft für ME/CFS**

This is not the only community effort in this area. Phoenix Rising, the community group for people with ME/CFS, curated a stock photography resource for journalists and media professionals to use royalty-free when writing articles about the illness (Phoenix Rising, 2016). Additionally, the German Association for ME commissioned 32 photographs depicting what it describes as the 'true burden of ME' (Deutsche Gesellschaft für ME/CFS, 2021). These photographs are available for free, copyright-free download if used by journalists who are reporting on the illness; two of these photographs are detailed below (see Figures 10 and 11). These images are dark in contrast and demonstrate the illness's sensory and mobility implications. Rather than portraying people resting, as is traditional in visual representations of the illness in the UK media, these images demonstrate restriction and suffering, and the inclusion of wheelchairs in the background signifies physical disability. By offering royalty-free kits, patients outsource symbolic capital to journalists under community terms, converting visibility into a controllable asset inside the media field.

This strategic use of imagery to counter invisibility resonates with wider disability activism. A recent example of this is the learning disability charity, Mencap's 'Do You See Me?' campaign (Mencap, 2023), which urges the public to 'see the person, not the learning disability.' While Mencap's campaign seeks to normalise disabled identity through positive and empowered visibility, the ME/CFS community's approach in *The Real ME* campaign adopts a contrasting logic of representation. Here, visibility is achieved not through aspirational normalcy but through the deliberate depiction of frailty and suffering, what Garland-Thomson (2009) articulates by arguing that 'we both need and dread the intense

recognition that staring accords' (p. 59).' These differing visual strategies highlight a politics of representation shaped by each community's social positioning. Where learning-disability activism must contest infantilisation, the ME/CFS community must combat invisibility. Both, however, engage in the affective labour of reconfiguring how disability is witnessed in the public sphere.

The following example illustrates how such visual activism evolves into a participatory relationship with mainstream media. During the netnographic process, four discussions were noted in which community members expressed dissatisfaction with the visual imagery being used by UK legacy media to depict ME/CFS. During these discussions, community members encouraged one another to write to media outlets, urging them to use Deutsche Gesellschaft für ME/CFS photography as an alternative. On one occasion, it was reported that the *Guardian* newspaper had listened, 'they've updated the article and changed to the image I suggested'. The language in these discussions suggested that this participatory networked activity was an empowering process.

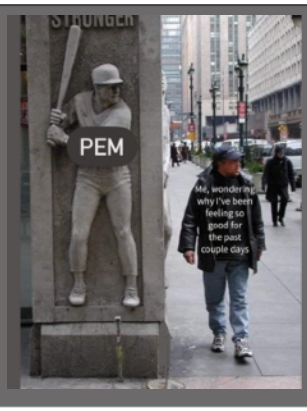
Such strategic engagement with media outlets reflects what Papacharissi (2015) terms an *affective public,* that is, a networked formation built through shared feeling and storytelling. By collaboratively lobbying journalists to replace trivialising stock imagery with authentic representations of suffering, the ME/CFS community performs affective boundary work, establishing what kinds of images are deemed accurate, ethical, and emotionally truthful. This mirrors patterns identified by Ellis and Goggin (2015), who argue that disabled people's online activism operates simultaneously as both media critique and care work, transforming digital participation into an act of collective advocacy. Through these image practices, participants convert emotion into political expression, challenging both stigma and misrepresentation. These acts amount to a form of participatory media governance, where patients function as de facto editors, ensuring representational accuracy, a reversal of traditional power hierarchies between subjects and producers. Together, these campaigns show how patients curate collective self-representation. The result is participatory media governance as patients act as editors, policing field boundaries around what counts as an "ethical" image of ME/CFS.

These findings resonate with Medcalf and Atkin's (2024) emphasis on the evolution of storytelling in the context of chronic illness, underscoring the potential of cyberspace to serve as a space for shared personal experiences and narratives. They argue for the value

of visual narratives in chronic disease management, positing that such representations can offer hope, education, and validation for both patients and the general public. They discuss how narrative frameworks articulated by patients not only aid in self-advocacy but also encourage the framing of chronic health conditions within a broader, more empathetic cultural context. Additionally, the characteristics of cyberspace have introduced new dimensions to visually representing chronic illness, with an increasingly greater number of chronically ill individuals utilising visual storytelling to contest societal narratives. In their research on how mothers of chronically ill children use cyberspace to manage their children's suffering, Wexler and Dole (2022) examine how caregivers and patients have adapted to the evolving media landscape, enabling nuanced portrayals of their experiences that starkly contrast with traditional media narratives, something clearly reflected in the findings of this thesis. This transformation empowers patients to connect, share, and reshape their narratives in ways that foster understanding and advocacy.

Memes, Humour, and Affective Solidarity

Another form of visual storytelling adopted by this community is the use of memes to relay information. Memes allow digital users to tell stories in a single moment and take many forms. Figures 12 and 13 detail memes generated through the netnographic process that use humour to convey the experiences associated with some of the illness's symptoms. The first focuses on PEM and the second on the chronic fatigue element. They use images that are traditionally unrelated to the illness but are widely understandable or recognisable.

Figure 12	Figure 13
	

Other memes, such as those seen in figures 14 and 15, are designed to emphasise the severity of the illness. Neither is elaborate nor detailed; however, both reflect severity and suffering in a snapshot.

Figure 14

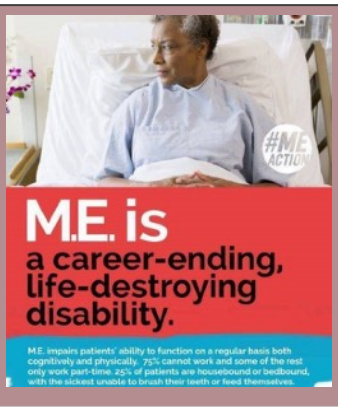


Figure 15

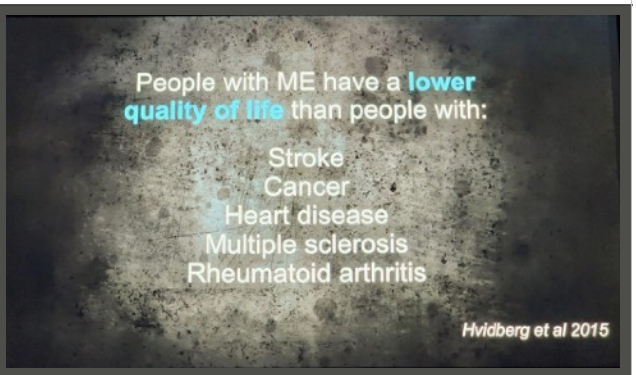


Figure 16

Other memes, such as the one detailed in Figure 16, are more focused on community building and encourage engagement through participatory practices such as liking, sharing and commenting. The meme practices observed here can also be situated within affective storytelling (Papacharissi, 2015), in which emotion circulates through small, shareable fragments that sustain digital publics. These memes operate as micro-narratives of both humour and critique, normalising experiences of illness while resisting the expectation of silence or stoicism often imposed on the chronically ill. In this respect, the visual humour of ME/CFS memes performs a dual function as it builds social cohesion within the community and simultaneously publicly contests the stigma of passivity and dependence that has long accompanied the illness. Such micro-acts of representation echo Garland-Thomson's (2009) assertion that every image of disability carries an invitation to stare, which is an opportunity to reconfigure the cultural meanings attached to witnessing.

These findings highlight how the community regards visual representation as central to public understanding and self-perception. Patient-led efforts to control imagery reshape how ME/CFS is depicted and challenge the hegemonic narratives that render it invisible. While this community actively engages with media outlets, the relationship remains asymmetrical, with patients proposing and journalists responding. The development of curated “journalist kits” and image banks demonstrates a strategy of targeted visibility. One that maximises recognition and accuracy while minimising personal exposure. In an attention economy that rewards spectacle, such low-waste visibility becomes both an act of advocacy and a form of self-protection.

Influencer Labour and the Politics of Authority

As previously discussed in Chapter 2, cyberspace is designed to reward visibility, engagement, and curated content, conditions that naturally give rise to 'influencers.' Influencers are individuals who gain traction by shaping compelling, often idealised narratives about their lives, reinforced through algorithmic promotion. As a result, the influencer economy tends to normalise and amplify highly stylised, distorted, and often unrealistic portrayals of lived experience, thereby obscuring the complexities of real life behind filters and carefully crafted captions. In their study of social media and its impact on perception, Udoudom et al. (2024) suggest that the symbolic interactionist and social constructionist frameworks provide essential insights into how communication practices in the influencer economy shape societal norms. They highlight how audiences reinterpret messages, with followers actively participating in identity formation shaped by often distorted representations, thereby strengthening the link between influencer content and identity.

The analysis of ME/CFS community influencers further illuminates how authority and trust are configured within this *political–biosocial habitus*. The architectures of cyberspace reward visibility, yet within the ME/CFS community, visibility is reframed as labour rather than spectacle. The practices of both medical and patient influencers demonstrate how the community translates individual advocacy into collective infrastructure. This section, therefore, explores influencer labour as a site where the pharmakon is again apparent, with its curative potential lying in the production of shared knowledge and solidarity, and its toxic potential in over-concentration of authority and burnout.

However, within disability and chronic illness communities, a different kind of influencer emerges. These individuals also build followings, but often by foregrounding vulnerability, advocacy, and truth-telling about the challenges of navigating health systems, social stigma, and fluctuating symptoms (Roy & Malloy, 2023). While some adopt mainstream influencer aesthetics, many intentionally resist overly polished content to preserve authenticity and foster solidarity. Still, they must navigate the same pressures of visibility and engagement, leading to difficult decisions about how much to disclose and how to represent their conditions.

In both cases, influencers operate under similar platform logics, but those in the disability and chronic illness spaces often repurpose the medium to raise awareness, challenge misconceptions, and build community rather than merely entertain or promote aspirational lifestyles. They blend content genres of lifestyle content with campaigning. During both the netnographic and interview processes, participants referenced and discussed online influencers from the ME/CFS community. Within this section, I distinguish two archetypes of influencer: (1) medical influencers, who mediate between biomedical fields and patient publics, and (2) patient influencers, whose authority derives from lived experience, peer labour, and organisational credibility. This distinction clarifies how symbolic and epistemic capital circulate across different professional and experiential strata of this *habitus*.

Medical influencers

There is a small but influential group of UK doctors who have earned deep trust within the ME/CFS community by advocating for biomedical research and visibly standing with patients. During interviews and netnographic data collection, the three figures consistently cited were Dr Charles Shepherd, Dr Amolak Singh Bansal, and Dr Sarah Myhill. Each demonstrates how medical authority is reconfigured in this community through both expertise and moral solidarity. These clinicians utilise social media and other digital platforms to disseminate biomedical information about ME/CFS while engaging with patients through openness, responsiveness, and friendly compassion. I refer to them here as “influencers” not in a commercial or aspirational sense, but because they are collectively recognised and celebrated within online patient communities as authoritative knowledge brokers. Their influence comes from their epistemic credibility, engagement with ME/CFS literature and knowledge-building, and their proximity to the medical field of power, by virtue of their medical doctorates.

Dr Charles Shepherd, medical adviser to the ME Association, is widely regarded as the community’s most trusted clinician. Author of *The ME/CFS/PVFS Clinical & Research Guide* (Shepherd, 2022), known within the community as the “Purple Book” due to its dust jacket colour, interacts directly with patients on social media, responding to posts and queries in a manner that fosters unusual familiarity between doctor and patient. His name appeared 346 times in the dataset, often affectionately shortened to “Dr Charles.” Seventeen references were made to the Purple Book, and all fourteen participants cited him as someone ‘you can trust’ or ‘who’s working for us.’ His MEpedia entry (Charles

Shepherd, 2023) catalogues decades of publications, advocacy, and media engagement, thereby reinforcing his role as both an insider and an ally.

Dr Amolak Singh Bansal, consultant immunologist, is similarly respected for his biomedical orientation and for treating patients as credible experts on their own illness. He developed the Bansal Score Chart, a diagnostic tool evaluating PEM, cognitive dysfunction, and hypersensitivity, and his clinical interest in immune abnormalities has made him a figure of hope. Community members frequently discuss his willingness to prescribe low-dose naltrexone and aripiprazole (Abilify). Typical comments referring to him in the netnographic data were: ‘You need to get referred to Bansal if you have any hope of getting prescribed that,’ and ‘I finally feel like someone’s looking after my health.’ The nickname ‘Bansal’ was also frequently used as one might speak of a friend, and signalled warmth and accessibility. Forum discussions often revolved around how to obtain referrals, and his MEpedia page (Amolak Bansal, 2023) consolidates his standing as an accessible biomedical authority.

Dr Sarah Myhill represents a more polarising but equally prominent presence. Formerly an NHS GP, she established a private practice in Powys focusing on ME/CFS and related chronic illnesses. Her work emphasises mitochondrial dysfunction, diet, and supplementation, and she has published studies and developed the “Mitochondrial Energy Score” test. She is also an outspoken critic of the PACE trial and the biopsychosocial model, and founded the MAIMES (Medical Abuse in ME Sufferers) campaign. Her name appeared 47 times in the dataset, usually as ‘Dr Sarah’, again indicating familiarity. As one participant wrote, ‘Her approach is too harsh on our systems,’ while another countered, ‘Getting well is hard you have to put the work in.’ Her MEpedia entry (Myhill, 2024) documents both her scientific work and her long-standing advocacy.

What unites these three doctors is that each has, in different ways, “suffered for the cause” so to speak. Their professional conflicts with institutions mirror the community’s own history of marginalisation. Dr Shepherd’s temporary dismissal from the ME Association after publicly criticising its governance (Dyer, 2003), Dr Bansal’s reported removal from NHS services in favour of psychiatric framing, and Dr Myhill’s repeated investigations and suspensions by the General Medical Council all exemplify risk-taking on behalf of patients. Such experiences are widely read as moral proof of commitment: as one forum member put it, ‘They fight for us because they’ve been through it too.’ Their trajectories illustrate

conversion between capital forms, for example, professional risk (cost) translated into moral-epistemic credibility and *suffering-capital* (asset) recognised by the patient field.

This solidarity through sanctioned dissent explains the moral and epistemic trust these clinicians command. They are respected not only for their biomedical expertise but for their willingness to challenge authority. By contrast, everyday encounters with general practitioners often generate frustration and disbelief. Only one interviewed participant described her GP as ‘excellent’ (Participant G), crediting her with ‘saving me from myself' through guidance on pacing and symptom management. The remaining participants spoke of diagnostic delay, disbelief, or gaslighting and nine claimed to know more about current protocols than their doctors. These findings highlight the persistent fracture of trust between this patient population and mainstream medicine, underscoring the need for co-produced research and care frameworks that recognise patient expertise as essential rather than supplementary.

Patient influencers

Another notable finding was the way this patient community discussed patient influencers. These patient influencers, rather than focusing on sharing lifestyle practices or aspirational narratives, publicly offered work products to online communities. For example, one of the forums that was the focus of this netnographic study was a forum established to offer advice to people with ME/CFS on navigating the UK benefits system. The forum has over 31,000 members and has 20 group moderators. The moderators maintain the content posted, remove posts that aren’t relevant to the group's remit, close discussions when they have been exhausted, and syndicate databases of literature they have compiled on applying for benefits and navigating the application process. What emerged from spending time in this forum was that certain moderators were treated as having great authority on the matter, and they were often referred to by their first names. For example, 'this is complicated, we should wait for [firstname] to come online and see what she says'.

There were also declarations of thanks in these forums, from people who had been denied benefits multiple times because they hadn’t known how to describe certain aspects of their illness in widely understood terms. These would include statements such as 'thank you so much [firstname] you are a hero! […] I did exactly what you said and finally I have been awarded PIP after 6 years of trying', and 'I just have to share my experience of my third attempt to get PIP, I was successful! […] I cannot thank you enough [firstname], you are

everything!'. Moderators from this same group were mentioned by first name and first and second names by five of the participants I interviewed. Four of them declared that they would not have been able to navigate the benefits system without the help of certain moderators and this group. Interestingly, the fifth hadn't needed to apply for benefits, but had joined the group and downloaded literature and advice that had been syndicated there, as part of her own personal 'toolkit of data', so it was there for her should she need to use it. This demonstrates the lengthy extent to which some in this community go in seeking information sources, not just out of immediate necessity, but also for future planning. Other patient influencers that were mentioned were those who ran webinars, created video content, offered training in treatment protocols and facilitated communications between government bodies and the community.

Those interviewed also shared ways in which they acted as influencers and advocates for people with ME/CFS. Three participants described taking on roles where their responsibility was to deliver advocacy and awareness training. One participant shared that this is now their only job.

> I work part-time for a charity that delivers disability equality training to local businesses and charities in the Bristol area. My role is to talk about my ME to groups of 10-20 people and explain how it affects me day to day and what others can do to help disabled people in their workplace. Sometimes these are online, and sometimes these are in person. This was very helpful and empowering. I am not ashamed of my condition, and I am ready to challenge any negative perceptions that people may have in a calm way (Participant K).

Two other participants shared that they are now involved in their employer's EDI training. One of them reported making information videos about ME/CFS that could be syndicated around the company, online, and at conferences. Another shared:

> I used my experience to chair an ED&I group at work. I joined the disability group and found that most of my colleagues in the group were carers for people with disabilities rather than those who suffered themselves. This puts me in a unique position to talk to the rest of the workforce about my experience and bring to their attention, in particular, hidden disabilities like CFS/ME & fibromyalgia. This has given me a lot of pleasure and a sense of value; I have become passionate about the subject and share a lot about workplace EDI online, and although I have missed a lot of work this year. I'm hoping to pick it back up again once I return. As someone who, prior to contracting this condition, was a very positive person who would change things I was unhappy with, accepting my loss of control has been the hardest part; and chairing the disability ed&I group at work has given me back a sense of purpose. I have also expanded my skills by chairing a group in this way, learned about disability tools online like [technologies that facilitate reading or data

> processing, online communication tools], and have been involved in our Company's processes to use these and also to help sort of build company-wide knowledge about this illness. I find this sort of communication very positive, at a time when not much is for me! (Participant D).

Participant D's articulation of communicating about illness and sharing it with wider communities as something positive and also nurturing for themselves demonstrates how communicating suffering through narratives of personal lived experience is multi-beneficial, both for information and awareness building and for validation and identity for those suffering. Such roles exemplify a shift from influence as image and identity to influence as infrastructure. Authority is earned through curation, moderation, and the maintenance of collective knowledge resources rather than through personal branding. However, this model depends on sustained volunteer labour and transparent moderation protocols and without institutional support, these micro-institutions remain vulnerable to fatigue and turnover.

Participants also volunteered information on how they engage in community-influencing practices through content creation. Seven of those interviewed shared blogs they had written, which focused on describing symptoms of the illness to raise awareness, articles designed to assist carers of individuals with ME/CFS, experiences of trialling medications, including both positive and negative responses, guides to pacing, and guides about their experiences with dietary restrictions. One participant who regularly writes blogs shared;

> So my mission is to raise awareness. You know, I'll write little articles. I've written books, and I'm currently working on a detective novel at the moment, and the detective has got ME. I've built a big following on Facebook of about 1400 people or so. I'll post my writing there, and when I release a new book, the community is really good at sharing it. […] I think that while the books provide entertainment, it's important that we are also represented in the normal and the everyday; otherwise, we are sort of invisible in everyday society. […] That's why I am writing crime fiction now; everyone likes a good bit of crime fiction (Participant C).

His disclosure demonstrates his drive to normalise representation. As much as he writes blogs that focus on the experience of living with ME/CFS, he also wants to champion the representation of the illness in what he refers to as the 'everyday'. This distinction, much like Participant D's expression that 'prior to contracting this condition, was a very positive person who would change things I was unhappy with', also resonates with this idea that patients don't want all the narratives about them to be driven by their suffering. These findings also reveal that what is distinctive about many ME/CFS influencers is their

departure from the typical trajectory of personal-brand storytelling found in mainstream influencer culture. Rather than representing their own lives as aspirational or performative content, these individuals often emerge as active helpers, educators, organisers, and advocates deeply rooted in the community. Their influence arises less from self-promotion and more from service. These influencers create accessible resources, lead advocacy efforts, share scientific research, and foster networks of care. This shift from personal visibility to communal labour represents a unique model of influence grounded in mutual aid and activism rather than lifestyle curation. Influencer labour is *pharmacological*. The same platform logics that elevate reliable moderators and clinician-allies can over-concentrate authority, reproduce *doxa* (taken-for-granted claims), and fuel burnout among a small cadre of patient leaders. The community's counter-measures, such as documentation, peer moderation, and transparent revision practices, function as a form of institutionalised scepticism that helps keep influence tethered to service rather than spectacle.

Together, these forms of influencer labour, medical and patient, illustrate a collective strategy for redistributing epistemic authority. Both rely on moral credibility, visible service, and the conversion of lived suffering into trust. Where medical influencers mobilise dissent within professional hierarchies, patient influencers build micro-infrastructures of care that sustain daily navigation of welfare, work, and health systems. Across both, influence is a maintenance practice, a continual upkeep of information flows, relationships, and credibility. This reframing of influence as infrastructural rather than performative extends the *political–biosocial habitus* traced throughout the chapter. It also prepares the ground for the next chapter, where these community-based infrastructures confront formal institutions, such as the welfare state, policy frameworks, and media systems, testing how patient-produced authority translates within bureaucratic regimes.

Summary

Across databases, lexicons, image banks, and influencer labour, the ME/CFS community has assembled a low-waste, high-solidarity digital knowledge system that stabilises trust while rationing attention and visibility. *This political–biosocial habitus* is curative when it enables collaborative reading, standardised terminology, and co-produced research, and it is toxic when it concentrates authority, polices boundaries too tightly, or depends on precarious volunteer labour and platform infrastructures.

Conceptually, the chapter advances Bourdieu by showing *habitus* as reflexive and infrastructural within patient publics. Rather than a pre-reflexive set of dispositions, the *political–biosocial habitus* is deliberately cultivated through collective protocols such as terminology rules, moderation practices, and “easy-read” norms that convert *suffering-capital* into epistemic and symbolic capital. Empirically, these routines reposition patients within the health-knowledge field, reshaping who may define credible evidence, appropriate language, and ethical images. In this way, the chapter demonstrates how digital infrastructures both express and reproduce a reconfigured *habitus* that redistributes symbolic power within fields such as media and medicine.

At the same time, these findings clarify the limits of *habitus* in the face of wider fields of power. Funding regimes, platform dependencies, and policy vetoes set the outer boundaries of what patient-led infrastructures can build and sustain. Practically, the analysis yields design principles such as transparent governance, accessible formats, mirrored storage, and shared custodianship that support durability and inclusion while mitigating gatekeeping and burnout.

The next chapter follows this ME/CFS *political–biosocial habitus* into society’s formal arenas of welfare adjudication, media campaigns, and policy, where fluctuating and invisible impairment meets rigid tests of proof. It examines the emotional politics of disability pride and shame, critiques the limits of the social model for energy-limiting conditions, and develops an interactional framework centred on fluctuation, relationality, and frailty as a practical route to fairer care and welfare.

CHAPTER 6: FINDINGS AND DISCUSSION, PART 3, ME/CFS, SOCIETY AND THE POLITICS OF DISABILITY

Introduction

Chapters 4 and 5 of this thesis examined how individuals with ME/CFS have responded to institutional neglect by cultivating a digitally networked epistemic culture. From the emergence of a biosocial collective shaped by shared affliction and mutual trust to the construction of patient-led healthcare protocols in digital spaces, the findings demonstrate that the online ME/CFS community has exhibited remarkable resilience and innovation. In doing so, it has redefined the traditional boundaries of expertise, legitimacy, and care. However, these grassroots infrastructures, while powerful, do not exist in a vacuum. They operate in constant tension with broader societal systems that often remain hostile, inadequate, or indifferent to the complexities of chronic illness. This discussion will build on these foundations to explore how people with ME/CFS engage with broader societal structures, particularly the UK benefits system and the government. It interrogates the emotional and political negotiations between disability pride and disability shame, examining how people with ME/CFS navigate both personal identity and public stigma in environments that demand productivity, visibility, and proof. These tensions are especially pronounced in bureaucratic contexts where individuals are often compelled to translate subjective, fluctuating experiences into fixed, measurable criteria.

The chapter proceeds in four parts. First, it explores the emotional politics of disability pride and disability shame, showing how these affective states are patterned by neoliberal expectations of work and worth rather than by individual fragility. Second, it rethinks the social model of disability in light of ME/CFS, using patient narratives and digital cultural production to highlight both its continuing political value and its conceptual limits. Third, it analyses how people with ME/CFS navigate UK welfare and governance frameworks, including PIP assessments, online benefits forums and the *Millions Missing* campaign, to reveal how the state mechanises disbelief and how patients build alternative infrastructures of care. Finally, it proposes a frailty-informed, relational model of care that draws on feminist ethics and existing frailty frameworks to sketch a more adequate basis for clinical practice and welfare policy for those living with ME/CFS.

Disability Pride, Shame and the Politics of Recognition

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This analysis of ‘disability pride’ appears in this chapter on ME/CFS and society because pride and shame are not merely intrapsychic states; they are relational affects of institutions that demand proof, consistency and productivity. These affects help to explain patterned behaviours, for example, reluctance to claim benefits, strategic self-presentation in assessments or withdrawal from public life, that are otherwise misread as individual preference or “non-compliance”. In short, the emotional politics of disability is a mechanism through which governance is lived.

Defining Disability Pride in Chronically Ill Communities

‘Disability pride’ refers to a movement that celebrates disabled identities and rejects the notion of disability as negative or shameful. It emphasises acceptance, empowerment and visibility, encouraging individuals to embrace disability as integral to identity rather than as something to overcome (Martin, 2012; Qin et al., 2025). Chronically ill communities, such as those with ME/CFS, have increasingly adopted the term to validate their experiences and advocate for recognition. Many individuals with chronic illnesses face scepticism, isolation, or pressure to 'pass' as non-disabled because their conditions aren’t always outwardly visible. By aligning themselves with disability pride, these communities can affirm their place within the broader disability movement and highlight the diverse ways disability manifests (Violet, 2022).

Cyberspace has significantly contributed to this movement by offering venues for chronically ill individuals to share their stories, unite around shared challenges, and seek solidarity. Hashtags such as #DisabilityPride and #ChronicallyIllAndProud have been instrumental in cultivating a sense of community and belonging. By leveraging social media, both individuals and organisations can champion disability pride, using hashtags and campaigns to enhance awareness. Diaz et al. (2023) underscore the crucial role Twitter played during the COVID-19 pandemic in enabling disabled individuals to express their challenges and fight for their rights. This illustrates a notable degree of organisation and solidarity, indicating that the adoption of disability pride constitutes a strategic response to societal stigma. Viewed this way, disability pride is not just a celebration of identity but also a powerful tool for collective advocacy, working to dismantle stigma and advocating for systemic changes that benefit all disabled individuals, regardless of whether their disabilities are visible or invisible.

Pride, Identity Reconstruction and Community After Onset

During the netnographic process, there were 67 instances of netnographic comments, including the hashtags #DisabilityPride, #ChronicallyIllAndProud, and #MEpride. Participants discussed disability pride directly in interviews. Participant H explained,

> Following disability activists on Twitter/X taught me the concept of disability pride and helped me see the various similarities and differences in the way that different kinds of disabled people are treated by society, which felt like an important part of personal growth.

Other participants also spoke honestly and reflectively about what disability pride meant to them, and their testimonials are particularly relevat because they reveal pride not as a given, but as something slowly and often painfully arrived at. Participant N, for instance, described how their undergraduate dissertation had explored the experience of living with ME/CFS through the framework of the five stages of grief. 'You have to work through the five stages of grief to cope with having a chronic illness,' they explained. After interviewing others with ME/CFS at a support group in Cardiff, what struck them most was the variation in emotional responses to having ME/CFS. Some people were still angry, while others had reached a place of acceptance, and some even felt 'proud of their ME.' This insight frames disability pride as an evolving emotional process rather than a fixed state.

Other participants provided accounts that illustrated how this pride was often interwoven with activism, self-advocacy, and resilience. Participant F, for example, spoke confidently about confronting ableism in everyday life, saying, 'I am not ashamed of my condition, and I am ready to challenge any negative perceptions that people may have in a calm way.' Here, pride was not merely personal but political, a stance taken deliberately in response to stigma. Similarly, Participant E emphasised the importance of disclosing her condition to those around her, particularly given the increased (though still limited) awareness associated with long COVID. 'Activities which are a part of everyday life for a healthy individual […] are all mired in a complex series of calculations for someone with ME,' she said. Her decision to share these details was not only informative but a proud refusal to remain silent about the complexities of her daily life.

This sense of pride also emerged in stories of social reorientation. Participant M, for instance, reflected on the abandonment by friends after becoming ill but reframed the loss as a turning point: 'My healthy friends vanished quickly, but I have made new friends who

have ME and understand, I kind of had a friendship upgrade.' Her comment, both humorous and poignant, reflects how disability pride often arises from community and connection with others who share similar experiences. For others, pride was deeply tied to their identity and to their bodies. Participant D, for example, recounted an experience on a first date where, despite having disclosed his illness, the woman reacted with alarm upon seeing his wheelchair: 'Oh god, how ill are you?' he recalled her saying. His response was resolute: 'I am proud of who I am, and my chair is part of me.' This assertion captures a powerful sense of embodiment and a pride that does not try to separate the self from illness or from the visible markers of disability. Taken together, these accounts complicate any simplistic notion of disability pride. They show it as layered, relational, and dynamic, emerging through grief, shaped by exclusion, and sustained through storytelling, community, and resistance.

These narratives reflect strength but also allow space for the vulnerability, loss, and transformation that often precede it. Beyond these emotional trajectories, participants also reflected on how their sense of identity and belonging were shaped by how others recognised, or failed to recognise, their condition. Several of the interviewees' accounts also underline the importance of having a socially recognisable disability label as a precondition for pride. Empirical work on disability identity suggests that self-identifying as disabled and claiming the category can enable people to reinterpret stigma, develop disability pride and experience better well-being (Bogart, 2017). For a condition such as ME/CFS, whose diagnostic status and legitimacy have long been contested, being able to say "I am disabled" or "I have ME" in ways that are understood by employers, clinicians, and the state can function as an anchor for pride.

Some expressions of pride echoed the "supercrip" narrative, celebrating perseverance and independence (Silva and Howe, 2012; Young, 2014). When Participant J insisted, 'I'm not a taker', and others foregrounded their pre-illness work ethic or the fact that they were not benefit claimants, their expressions of pride implicitly distinguished themselves from an imagined "other" disabled subject who is dependent, passive or morally suspect. In this way, disability pride can unintentionally reproduce hierarchies within disability, legitimising some ways of being disabled while further stigmatising those who cannot or will not conform to the supercrip expectations mentioned previously in Chapter 2 (Barnes, 1992; Clare, 1999; Young, 2014; Wolbring, 2024).

These internal hierarchies within disability culture highlight the complexity of identity reconstruction following the onset of chronic illness. Botha and Harvey (2024) show that adults with acquired disabilities reconstruct their identities through collective strategies of solidarity and advocacy, reminding us that disability pride is plural and shaped by diverse experiences. In this way, the findings of this thesis demonstrate that the restructuring of identity and the adoption of disability pride are, for some, a positive and significant process of framing and committing to a new way of living. However, it must also be acknowledged that it is often not a passive action. Instead, it is a balancing of social agreements and practices, and frequently arises in response to social and structural othering that organise to elicit not pride but shame. Indeed, disability pride and shame are not opposing states, as Goffman (1963) presses, ‘the role of normal and the role of stigmatized are parts of the same complex, cuts from the same standard cloth’ (p. 131).

Drawing on Weiss (1999), intercorporeality helps explain how bodily identity is shaped through relations with others. Pride may emerge through solidarity and mutual recognition, while shame can surface when the body is judged against norms of productivity and independence. Pride may emerge in moments of solidarity, mutual recognition, or collective empowerment, particularly within disability communities that affirm shared experiences. Conversely, shame can arise when one’s body is perceived as 'failing' to meet societal expectations of productivity, independence, or normalcy, especially in interactions with able-bodied others or institutional systems. In Goffman’s terms, ’The stigmatized individual may find that he feels unsure of how we normals will identify him and receive him’ (Goffman, 1963, p.13), and the ‘stigmatized individual is asked to act so as to imply neither that his burden is heavy nor that bearing it has made him different from us’ (p. 123). These experiences are relational, shaped by social encounters that structure the emotional and political landscape of chronic illness.

From Pride to Shame: Work, Worth and Neoliberal Suspicion

Where participants in this study often spoke of disability pride, their remarks were intertwined with stories that unveiled a more intricate emotional landscape, where pride was frequently accompanied, or even undermined, by lingering feelings of shame. Many participants felt a persistent need to validate their legitimacy as disabled individuals by recounting who they had once been. Their journal entries often began with detailed descriptions of life prior to illness, as if setting the scene not only for the onset of ME/CFS but also for an ongoing negotiation of self-worth.

Participants emphasised that they had once been high achievers, diligent workers, and devoted athletes. One participant remarked that they had been an Olympic athlete, while others remembered running marathons, competing in dance, working extensive hours, or leading full, ‘productive’ lives. These were not incidental memories or mere declarations of loss, they served as a form of moral alibi, an endeavour to counter the suspicion that their current limitations were somehow a matter of choice, weakness, or lack of effort.

This impulse to justify their illness extended into the interview space as well. Participants often worked to manage the impressions they believed others, including myself as the interviewer, might form of them. One participant (J) stated flatly, 'I would never apply for benefits […] I’m not a taker' despite later revealing that they were fortunate enough to avoid doing so because of financial support from wealthy parents. However, the subtext was clear, claiming disability support was associated with embarrassment, along with a sense of failure or dependence that they felt needed to be disavowed. Others were keen to share details of their employment history before they developed ME/CFS, referencing that they were on a 'high wage' or that they had private healthcare from their 'very good job'. Such remarks highlighted how deeply entangled disability pride was with a fear of being seen as undeserving or morally suspect. These findings align with Fadyl et al.’s (2015) biopolitical critique of the discourses of self-worth linked to health and employment. They argue that,

> Discourses that employment demonstrates or enhances a person’s worth appear in various ways in vocational rehabilitation texts. In arguments promoting the employment of disabled people, it is sometimes suggested that through paid work, a person is given the opportunity to enhance their potential, which also communicates a statement that unemployed individuals are not realising their potential (Fadyl et al., 2015, p. 510).

These narratives of moral worth intersect closely with what other disability theorists identify as the contradictory expectations placed on disabled people in neoliberal societies.

Runswick-Cole and Goodley (2013) similarly argue that disabled people are positioned in a contradictory way within neoliberal-ableist cultures. They must demonstrate that they are “impaired enough” to warrant care, support, and legal protection, while simultaneously presenting as resilient, positive, and self-managing subjects who do not rely too heavily on those same systems (Runswick-Cole and Goodley, 2013; Goodley, 2014). This ambivalent demand helps explain why participants in this study oscillated between asserting disability

pride and disavowing dependence or benefit receipt, as pride becomes thinkable only when accompanied by assurances of hard work, stoicism, and minimal burden on others.

In this context, worth and value are fundamentally tied to economic productivity. Foucault's (1977) idea of normalisation is particularly relevant here. While discussing one's job can be empowering and can strengthen positive social perceptions in various situations, it may inadvertently reinforce norms that dictate "acceptable" ways of living, marginalising those who do not conform. For instance, biopolitical governance frequently prioritises productivity and economic utility in relation to disability. Research conducted by Shakespeare et al. (2016) contends that disability is often reframed in ways that cater to economic assessments, commodifying the lives of disabled individuals rather than affirming their intrinsic dignity.

These tensions were also evident in the netnographic data, where participants discussed the everyday strategies they employed to conceal their condition or minimise its visibility. Several people described a kind of performance of pushing themselves to appear capable, even when the cost was severe. One participant admitted, 'I'm so embarrassed when I have to say I can't do it […] so I end up doing it and then for weeks afterwards […] my PEM is so bad I can't prepare food or wash or anything.' Another explained that while they always tell people they had ME, they still made disingenuous excuses to avoid activities, stating, 'I say I have another appointment or something, instead of just saying I know I look fine right now but I am dying inside.' The fear of being perceived as 'pathetic' or as someone who 'can't do anything' led many to hide their symptoms, even from those close to them. For some, this concealment extended to the most ordinary aspects of daily life. One participant recounted lying to a friend about watching *The Handmaid's Tale*, not because they had no interest in it, but because sensory overload made watching television impossible. 'I was too embarrassed to say I can't do that anymore […] so I googled a synopsis and pretended I'd seen it,' they explained. In another example, a participant helped with Christmas dinner, despite knowing it was too much. 'Everyone expected me to help,' they wrote, and as a result, by Boxing Day, they were 'back in hospital on another drip again'. Other commentators shared that they 'try not to use their mobility aids' because they don't want people to know how ill they are or because 'people always treat you differently when you are in your chair, don't they […] and then when they see you not in your chair they think you were making it up'. These moments illustrate how participants often felt caught between the desire to assert pride in their disabled identity and the

compulsion to mitigate it, to appear as capable, productive, and as 'normal' as possible. Pride, in this context, wasn't a fixed state but something constantly negotiated and shaped as much by internalised ableism and social pressure as by personal acceptance or affirmation.

Shame is a complex emotional response often arising from social stigma and societal expectations related to illness. Dolezal and Lyons (2017) articulate that health-related shame can manifest as an internalised response to societal perceptions, leading individuals to feel unworthy due to their health status. Their work emphasises that chronic shame can significantly impact well-being and social interactions, often leading to avoidance of social situations where individuals fear exposure to judgment. Yeo et al. (2024) further explore the relationships between shame and clinical outcomes in individuals with knee osteoarthritis, revealing that shame not only affects immediate well-being but can have long-term implications on disease management. The persistence of shame experienced by individuals with chronic health conditions raises critical questions about how shame can influence their willingness to both seek care and adhere to treatment recommendations.

In this light, the communal aspect of addressing shame cannot be overstated. Online and offline communities provide spaces where individuals can share their experiences of both pride and shame, validate their feelings, and confront the stigma associated with chronic illness. Suratwala (2024) relates how the shared experiences of individuals with eating disorders reveal that the discussion and articulation of shame can facilitate recovery and social support. This underscores the importance of peer support in breaking down shame, suggesting that collective advocacy can transform narratives surrounding chronic health.

The narratives that have arisen in this study demonstrate how these communities foster an environment where individuals can reclaim their identities and promote disability pride whilst also discussing disability shame, but they also highlight the relationally and socially constituted nature of disability. Taken together, these accounts show that disability pride and disability shame are patterned by institutional demands rather than personal fragility alone. This tension resonates with recent critical disability scholarship. Goodley, Liddiard and Runswick-Cole (2018) describe a similar affective economy as a form of ontological invalidation characteristic of neoliberal-able times, in which disabled people are simultaneously urged to embody hopeful, resilient citizens and required to prove, again

and again, the authenticity of their debility. The need to appear capable enough for social acceptance yet impaired enough for eligibility reveals a structural double bind. This double bind points directly to the limits of the social model for energy-limiting, unstable conditions.

These emotional contradictions, such as the demand to be simultaneously resilient and dependent, proud yet apologetic, are not only personal struggles but also reveal theoretical limits in how disability itself is conceptualised. In particular, they highlight where the social model, while politically indispensable, struggles to capture the embodied, unstable realities of energy-limiting illness. It is to these tensions that the following section now turns. These affective contradictions are not incidental. They are produced by a wider disability imaginary in which legitimacy is tied to stability, visibility and predictable performance. In that context, fluctuation is easily misread as inconsistency, and invisibility becomes grounds for suspicion rather than a recognised mode of impairment. This helps explain why participants oscillated between asserting disability pride and managing shame: the emotional double bind is the lived expression of a conceptual and institutional demand for legible, measurable disability. It is precisely here that the social model's usual explanatory grammar begins to strain for energy-limiting illness.

Rethinking the Social Model of Disability for ME/CFS

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The social model of disability distinguishes between individual impairment and the societal barriers that affect people. It asserts that people are disabled not by impairments but by social, attitudinal and environmental obstacles (Oliver, 1990). Social-model language has been adopted in UK policy and guidance, yet this study's findings demonstrate both participants' awareness of it and their frustration with its limitations.

'The Social Model Doesn't Work for Us': Bodily Limits in ME/CFS

Participant H mentioned in their journal that 'the social model of disability doesn't work for us […] it isn't relevant'. When asked to expand on this during the interview process, they said,

> Well, I feel like this idea of being disabled by society doesn't fit for ME/CFS. […] There's also just the fact that you know, no number of accommodations are gonna make me capable of using public transport or, you know, going out and getting a job or anything like that. I think when there are so many different things wrong with your body all at once, and like no amount of education and resources and stuff coming from society is going to make a difference. […] You know it, it's just very different from say just being visually impaired and you know needing a cane and a dog or you know what, whatever. […] I don't think there ever could be a social fix for ME. Moving can be too much for us, even if we are being pushed in a chair. How does society accommodate that? How does society accommodate people who will collapse if there is noise or light?

Participant H's reflections challenge the adequacy of the social model for conditions like ME/CFS. Their statement that 'the social model of disability doesn't work for us […] it isn't relevant' raises questions about a model that foregrounds social barriers but underplays severe, persistent bodily limits. No amount of assistive technology, accessibility or awareness can fully mitigate the impact of symptoms such as post-exertional malaise, sensory sensitivity and cognitive dysfunction. Being unable to tolerate light, sound or movement, even when environmental barriers are removed through aids such as a wheelchair, illustrates a form of embodied limitation that cannot be adequately addressed by the social model's emphasis on inclusion through access alone. Participant H provides a convincing argument that for some people, participation is not only structurally obstructed but somatically impossible.

Digital Memes as Grassroots Disability Theory

Netnographic findings also demonstrated that the ME/CFS online community actively engages with and critiques the social model of disability. Cultural production becomes a tool of political commentary and epistemic resistance. Three memes are described here (rather than reproduced) to protect participants and avoid traceability within a semi-private Facebook space. Each features the text ‘ME says fuck the social model of disability’ and offers visual metaphors that subvert its traditional logic.

The first depicts a woman lying on the ground asleep behind a lowered wall. In conventional social model imagery, barriers like walls are often used to symbolise exclusion, with solutions depicted as ramps, lowered walls, or ladders. This meme directly critiques the limitations of that imagery. The wall has been lowered, presumably indicating that a social barrier has been removed; however, the individual remains incapacitated. The image makes a powerful statement that if the body is too depleted to function, environmental accessibility is insufficient. It challenges the foundational assumption of the social model, that it is primarily barriers, not impairments, that disable people. It also introduces a critical dialogue about energy, embodiment, and incapacity that the model tends to overlook.

The second shows a man collapsed on the ground, physically plugged into a factory draining his personal battery. The metaphor speaks to the extractive nature of neoliberal productivity culture, suggesting that social support cannot resolve a problem rooted in demands that exceed bodily capacity.

The third depicts a sleeping woman sat at a her desk in front of a computer, being manipulated by strings like a puppet, evoking coercive expectations to perform, work and appear ‘normal’ even when such performance is harmful. Her limp body contrasts with forced movement, illustrating the disconnect between appearance and ability and the cost of constant performativity.

These images demonstrate both familiarity with and disillusionment towards the social model. This is not a community unaware of its historical significance but one that has engaged deeply enough to identify its exclusions and articulate new demands. Memes here are not simply jokes but acts of cultural critique and knowledge production that raise questions about whose suffering is recognised and how it is made legible. Developed

largely with visible, mobility-related impairments in mind, the social model struggles with conditions characterised by invisibility, fluctuation and contested legitimacy.

This limitation is clear in Goodley's critique of how learning disability is often treated as outside social-model thinking, where ' "learning difficulties" remains tacitly conceived of as a biological deficit' (Goodley, 2010, p. 210). By saying 'fuck the social model', these memes demand a framework that makes room for energy limitation, medical ambiguity and the interplay of social and biological constraints. These discussions are fascinating because they reflect a decentralised, grassroots reimagining of disability theory. They represent a moment where lived experience and academic discourse collide in productive tension, where users are using the tools of digital culture to carve out space for more inclusive frameworks. In doing so, they challenge researchers, policymakers, and activists alike to rethink what inclusion means, and for whom our models of disability are working and who they are failing.

Beyond the Social Model: Impairment, Pain and Neoliberal Convalescence

The social model has been central to disability rights advocacy, positing that disability arises from societal barriers rather than impairments alone. However, critiques, particularly from those with chronic illness, highlight its neglect of pain and impairment and its tendency to frame disability as a tragedy to be fixed (Crow, 1992; Hughes and Paterson, 1997; Shakespeare and Watson, 1997; Wendell, 1997; Goodley, 2010). In discussing the problems of the social model, Swain and French (2000) propose the 'affirmative model' of disability, a non-tragic view of disability and impairment. Their model

> directly challenges presumptions of personal tragedy and the determination of identity through the value-laden presumptions of non-disabled people. It signifies the rejection of presumptions of tragedy, alongside rejections of presumptions of dependency and abnormality. Whereas the social model is generated by disabled people's experiences within a disabling society, the affirmative model is borne of disabled people's experiences as valid individuals, as determining their own lifestyles, culture and identity. The social model sites 'the problem' within society; the affirmative model directly challenges the notion that 'the problem' lies within the individual or impairment (p. 578).

This affirmation model acts to counter disability shame and frames disability as a valid 'other' rather than a societal problem. Barnes (2016) develops a philosophical defence of this position, suggesting that disability should be viewed as value-neutral. Disability, in itself, is not inherently bad or detrimental to a person's well-being, but rather, the negative

aspects of disability often stem from social injustice, stigma, and a lack of access, rather than from the impairment itself, and Barnes suggests disability should be considered as a minority “other”. However, while these philosophical models effectively address the personal, societal and cultural relationship with disability, their treatment of impairment remains inadequate.

Crow (1992, p. 9) notes that ‘an impairment such as pain or chronic illness may curtail an individual’s activities so much that the restriction of the outside world becomes irrelevant’. Critiques of the social model, therefore, emphasise that chronic conditions involve both impairment and social barriers and resist a simple medical–social binary. Carel (2018) similarly argues that understanding disability and illness requires attention to the phenomenological body, showing how illness alters capacity for action, social participation and presence in the world. While social interaction may be dramatically modified without eliminating well-being, Carel stresses that ‘not all types of illness experience and not all symptoms permit well-being. Chronic pain is one such example’ (p. 130).

Shakespeare (2014), however, critiques these adjustments to theory, articulating that 'impairment and illness is often experienced not just as difference, but as difficulty and limitation and pain and suffering' (p. 84). He continues,

> until now, only two alternatives for conceptualising impairment have been available: (1) the traditional approach, what Michael Oliver calls the ‘medical tragedy theory’; and (2) the denial or neglect of impairment with materialist and constructionist approaches. I would argue that impairment and illness should not be regarded as the end of the world, tragic and pathological. But neither are these bodily experiences irrelevant, or just another difference. Many disabled people are unable to view impairment as neutral (ibid).

His argument underscores the need for an interactional approach that encompasses both individual and structural impact and particularly reaffirms the need for less binary approaches to conceptualising disability, where disability can be neutral for some, but absolutely not for others. I would also argue that any approach should allow for dialogue that distinguishes between disability and chronic health, which engages with the problem of pain and intolerable impairment.

It is also evident that the social model of disability, while often framed as emancipatory, remains deeply entwined with the logics of capitalism. This entanglement is evident in the

model's frequent mobilisation as a framework for integrating disabled and ill individuals into society, not primarily for holistic inclusion but for their optimal participation in economic productivity systems. Indeed, it is worth reconsidering the findings in Chapter 4 of this thesis, which explore how people with ME/CFS are using HRM as a tool to extract the maximum range of productivity from their bodies. Having previously discussed HRM as a form of benefit, a tool that can reap rewards when patients use it to mitigate periods of relapse and warn of PEM, I would also argue however, that the process encourages patients to focus on measuring their absolute potential productivity for the day, an act of labour itself, indeed, 'embodied invisible work can counter inaccurate but deeply embedded cognitive metaphors wherein illness and disability is conflated with passivity' (Grue, 2023, p. 87).

When evaluating contemporary feminist perspectives of illness and work, Groenvold (2024) refers to this as ‘patient work’ and argues that 'chronic illness is shaped by and against neoliberal capitalism and contemporary work culture' (p. 3). They conclude that Illness is not the 'antithesis to work but instead […] illness and work compound each other. With a rise in ‘patient work’ and an increasingly active sick role, illness entails administrative, reproductive, and investigative labour’ (ibid). Groenvold’s conclusions are evident in the findings of this, in which the labour of ‘patient work’ among this population constitutes a considerable contribution to our epistemology of ME/CFS.

Building on these feminist critiques of labour and productivity, Shildrick (2009) argues that dominant disability discourses are structured through imagining disability through the lens of deficit. This idea offers a further theoretical lens through which to understand this dynamic. She argues that within dominant biomedical and cultural discourses, the disabled body is persistently framed as incomplete or lacking, a deviation from the normative ideal of autonomy, coherence and productivity. Even within ostensibly emancipatory frameworks, such as the social model, this underlying logic of deficit can endure if social value continues to be measured through capacity, independence, or economic contribution. From this perspective, welfare and employment systems do not simply exclude disabled people but continuously reproduce the assumption that disability signifies absence, a gap to be compensated for through labour, rehabilitation or the performance of resilience. Such a view forecloses more pluralistic understandings of contribution and belonging, where interdependence, care, and lived expertise might be recognised as valuable forms of participation in their own right.

When discussing using HRM, participants during the netnography also made comments such as 'it means I can make sure I can do some part-time work from home […] see ok, if I wash and dress today I wont have the energy to work from home, that's going to cane my energy, but if I don't then I can get some work done', another who also worked from home said that for them HRM was 'really useful to find when I can do a few hours […] so sometimes it's not until 3am or whatever that I have capacity and it lets me squeeze that work in then', indicating the tool helps facilitate extracting economic production over basic acts of self-care such as washing, dressing and sleeping. Where there are clear benefits and ingenuity in using HRM, and it certainly can act as a tool to facilitate better knowledge of health, there is still a clear emphasis on enabling individuals to return to or approximate forms of labour deemed valuable by capitalist structures, rather than embracing a broader, pluralistic conception of human contribution. This orientation raises questions about the erasure of states such as convalescence, extended periods of rest, recovery, or altered temporalities that do not align neatly with capitalist imperatives. In this sense, convalescence becomes a mode of being that resists the productivity-driven frameworks dominant in both neoliberal and biopolitical understandings of disability and illness.

Penn et al. (2011) describe nineteenth-century convalescence homes as 'a unique type of institution' (p. 138), based on the understanding that industrialisation 'not only exacerbated ill health amongst the poor but also impeded the recovery of survivors' (p. 138). Removing people from structures of labour production and providing space and time to convalesce was seen as both moral and practical. This understanding has been systematically undermined. The implementation of "care in the community" during Margaret Thatcher's premiership as British Prime Minister marked an ideological shift driven by neoliberal imperatives of reduced public expenditure, privatisation, and market-based responsibility (Scott-Samuel et al., 2014). It also drew on the principle of 'normalisation' (Wolfensberger et al., 1972), developed in response to the stigmatising and segregating effects of institutionalisation documented in studies of learning disability (Edgerton, 1967) and shaped by wider sociological accounts of stigma (Goffman, 1963).

The closure of convalescence homes and long-term care facilities reflected what Fawcett and Hanlon (2009) call 'the commodification of [care] services' (p.45), subordinating the needs of chronically ill and disabled people to economic efficiency and marginalising convalescence as a socially sanctioned period of recovery. Convalescence, once regarded as a necessary and socially sanctioned open-ended period of recovery, has become

increasingly marginalised in both policy and culture. Where once there were spaces in which individuals could recover or stabilise outside of market demands, the dominant neoliberal ethos has reframed health in strictly economic terms: to be well is to be productive.

The consequences of this shift are profound. As Allan (2022) notes, care homes now operate in a highly competitive market, and closures frequently result from financial infeasibility rather than from issues with the quality or necessity of care. Glasby et al. (2018) observe that the research landscape has largely failed to keep pace with the reality of these closures, limiting our understanding of their long-term impact. Hutchinson et al. (2023) further highlight the broader consequences of healthcare facility closures, showing how disruptions in continuity of care, particularly for chronically ill individuals, can exacerbate existing vulnerabilities and undermine recovery.

Beyond these structural effects, the erosion of convalescence has reshaped the sociology of illness itself. Drawing on Carel's phenomenology of illness, this can be understood as a narrowing of the experiential space in which illness is allowed to unfold. Illness alters a person's orientation to the world and to embodied agency (Carel, 2018), yet in a culture that tolerates only bodies that quickly return to functionality, this altered state is delegitimised. Convalescence, which is slow and often indefinite, has little place within neoliberal demands for speed and visible outcomes.

Illich's critique of medicalisation further illuminates this transformation. In *Medical Nemesis* (1976), he argues that modern medicine has appropriated the role of healing, thereby stripping individuals and communities of autonomy. The closure of convalescence homes and the devaluation of non-productive states extend this logic, where health must be restored rapidly, and the sick person becomes a passive recipient of interventions aimed at reintegration into labour. Illness is no longer recognised as a human condition requiring time and recognition, but as a technical failure to be rectified. Those who remain unwell, unstable or dependent are left to navigate systems that neither accommodate their needs nor recognise their forms of life as socially valuable.

As Stewart (2019) highlights, the implementation of welfare reforms often reflects neoliberal priorities that favour employability over support, aligning with Foucault's idea of biopower, where the state governs bodies by shaping their access to resources and

services, effectively rendering them as subjects to control rather than empowering them. In discussing architectural harm through welfare reform, Stewart (2019) argues,

> The removal of the clinical opinion of family doctors for claimants of long-term sickness and disability benefit was destined to cause preventable harm with the adoption of IB in 1995. IB had replaced invalidity benefit, which was previously allocated using the opinion of the family doctor. IB was introduced with the adoption of the All Work Test, using a non-medical assessment conducted by doctors employed by the government (Stewart, 2019, p. 225).

In this manner, we can observe the state demoting the word of qualified medical practitioners and supplanting them with unqualified workers who align with the state agenda. The relationship between the social model and UK legislation has continued to evolve since the Disability Discrimination Act 1995 and the Equality Act 2010. Yet Bambra and Pope (2007) show that policy often falls short of implementing social model principles, and neoliberal and austerity measures have reduced support and exacerbated structural inequalities. The dynamics of pride and shame are therefore constitutive of welfare: they shape the language used on PIP forms, the evidence marshalled, willingness to disclose PEM, and the capacity to persist through reconsiderations and tribunals.

Having outlined the theoretical limits of current disability frameworks, it becomes necessary to examine how these limitations manifest in everyday governance. The next section turns to the UK welfare system, where policy, bureaucracy and disbelief converge to transform these theoretical tensions into lived administrative struggle. If the social model helps us name structural disablement, the benefits system shows how that disablement is administered: through descriptors, surveillance, and credibility tests that treat fluctuation as evidence against legitimacy. In other words, welfare governance operationalises the same ‘legibility rules’ that participants critique in disability theory, converting lived uncertainty into administrative risk.

Navigating ME/CFS within UK Welfare and Governance Frameworks

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This section explores how people with ME/CFS navigate the UK's welfare and benefits systems, primarily PIP, ESA and UC. These deeply bureaucratic structures involve strict criteria, points-based assessments and often confrontational adjudication. Extending the social model critique developed earlier, the benefits apparatus not only fails to accommodate people with ME/CFS but also actively disables them by transforming impairment into administrative disadvantage. As Oliver (1990) noted, disability lies not in the body but in society's organisation, and as Barnes (2019) argues, welfare bureaucracies continue to reproduce structural disablement despite claims of inclusion. While these benefits are theoretically intended to support individuals who face physical, cognitive, or psychological barriers to work and daily living, the practicalities of accessing them are immensely complex, particularly for those living with ME/CFS. PIP, the central benefit for disability-related costs, requires an extensive application form in which claimants must describe how their condition affects their ability to perform a set of prescribed tasks, ranging from preparing food and washing to mobility and communication. The form is followed by a medical assessment conducted by a contracted health professional who often lacks specialist knowledge of ME/CFS. The system is designed around observable, stable impairments, assuming a level of predictability and uniformity in how disability manifests. This is deeply problematic for ME/CFS sufferers, whose symptoms fluctuate unpredictably and include invisible yet debilitating impairments such as cognitive dysfunction, sensory sensitivity, and post-exertional malaise (PEM).

Online Benefits Forums as Alternative Welfare Infrastructure

In chapter 5 of this thesis, a forum was referenced that held 31,000 members and had 20 moderators. This forum serves as a critical community infrastructure for people navigating the deeply bureaucratic and often dehumanising process of applying for disability benefits, undergoing reassessments, or responding to benefit reviews. As previously discussed, this space functions as a peer-support network, an informal knowledge archive, and an emotional lifeline. Through user-led threads and comment sections, people share advice, vent frustrations, and collectively decode the opaque language and processes of the UK welfare system. Within this environment, the voices of the community are rich with insight into how the benefits regime mechanises and disqualifies suffering, particularly for those living with ME/CFS. A striking 211 comments were noted from the forum, which explicitly referenced difficulties navigating the PIP application process. Many of these comments

critically examine the language used by the Department for Work and Pensions (DWP), including terms such as 'awards,' 'descriptors,' and 'assessments.' These terms are not neutral. They imply achievement, merit, or objectivity.

Performing Illness in a Points-Based System

The very terms of assessment channel pride and shame into administrative labour, compelling claimants to narrate suffering in legally legible ways that often run counter to how ME/CFS is experienced. “Assessment” evokes clinical neutrality, yet many describe these assessments as fundamentally biased and uninformed. The word “award” suggests a prize for performance, creating a dynamic in which the claimant must perform suffering convincingly enough to be granted recognition. Grue (2023, p. 85), when discussing biopolitical interventions, argues that,

> For the sick role, health-seeking behaviour must be balanced against proper illness behaviour, that is, a demonstration that the illness is sufficiently serious to merit privileges of exemption. The same applies to disability privileges, that is, rights-based access to compensatory accommodation. In each case, the role becomes a balancing act, and a double bind is created, one that can be framed in terms of unacknowledged or invisible work.

One forum user captures the paradox at the heart of the application process, they shared,

> I just don’t understand what I am meant to put on this PIP form. I can walk 50 meters, sure, I can do that maybe every day in a week, but then I can’t even sit up for a month. I feel like I am a liar if I say no, I can’t do it, because I can literally do it, but only because I don’t do it.

This quote articulates the core difficulty that ME/CFS sufferers face, the mismatch between the binary, static questions on the PIP form and the dynamic, fluctuating nature of their illness. The language of the form flattens nuanced experiences into yes/no binaries that fail to capture conditions like PEM, which are delayed and cumulative. The forum serves as a space where users can validate each other’s ambivalence and confusion, offering language that helps navigate forms that are not designed to reflect their lived reality.

Another common theme is the psychological cost of interacting with the system. One user wrote:

> I just had my PIP review back and I have zero points on any of the descriptors. I feel so deflated. I spent two weeks filling in the forms and crashed so badly afterwards, and now I'm reading what they wrote about me […] it's like they didn't listen to a single thing I wrote or said […] I'm now in a full on crash.

This post reflects a dual injury, of both the physical toll of the bureaucratic labour required to fill out forms and the emotional toll of being disbelieved. That users must 'crash' in order to comply with institutional demands demonstrates the violence of a system that asks the sick to exhaust themselves to prove their suffering. Another user's experience further critiques the legitimacy of the assessment process:

> I was just awarded zero points, and the woman was really nice on the phone during the interview. I thought she was listening to me, but from the report, she clearly didn't understand anything I was saying about PEM. […] She also said because I wasn't on pain medication that my pain isn't substantial [but I had provided] pages and pages of evidence about why I can't take medication because it makes my ME worse.

Here, the user highlights a systemic failure in clinical literacy. The assessor overlooks the patient's self-report and medical advice due to a reliance on standardised assumptions, such as the presence of pain medication being a measure of real suffering. This illustrates how biomedical norms override the expertise of the patient and even other health professionals, reinforcing institutional disbelief. Another member recounts:

> Zero points! What a surprise. Can you guys help me? My report says that because I was able to speak during the interview, I don't have cognitive problems. Apparently, the assessor's opinion was more important than the supporting evidence [I provided from] my GP, my neurologist, my physiotherapist, and my carer that said otherwise.

This quote points to the systemic prioritisation of assessor perception over expert documentation. It highlights a key power imbalance in the assessment process, wherein momentary performance, such as being able to speak coherently, supersedes sustained evidence from a multidisciplinary team. The assessment becomes an act of surveillance rather than care, reinforcing a system that demands legibility on its own terms.

These testimonials demonstrate how navigating this system is not just physically demanding but also cognitively overwhelming. ME/CFS commonly involves 'brain fog,' memory loss, and impaired executive functioning. Claimants must gather medical evidence, understand legal terminology, construct narratives of impairment, and argue

their case in a framework that often demands the language and logic of under-resourced benefit assessors. Many report that the process itself causes deterioration in their health.

During the netnographic process, 34 instances were noted where people declared that filling in the forms had caused a direct and significant decline in their health. The energy required to manage deadlines, understand eligibility criteria, and appeal decisions can take weeks to recover from. For those who are severely affected, the idea of completing a benefits application without significant help is unrealistic. These findings highlight how the bureaucratic design of PIP conflicts with the lived reality of ME/CFS. Assessments rely on binary judgments, where one can or cannot perform a task. Yet, ME/CFS fluctuates daily. Brief interviews fail to capture delayed fatigue or post-exertional crashes, while poorly applied ‘reliability criteria’ often overstate claimants’ functionality.

However, this forum revealed that collaborative practices within it enhance success rates. Moderators provide evidence templates, explain grading criteria, advise on supporting documentation, and offer guidance on legal entitlement and tribunals. 43 Instances of community members thanking group moderators for successful applications were noted. Some referenced this through disclosures such as 'I did exactly what [group moderator] said this time and I have gone from zero points on everything to enhanced on care and standard on mobility' or '[group moderator] I cannot thank you enough I am totally gobsmacked. The templates you gave me were so helpful and understanding exactly how they score and how to explain PEM was so helpful'. Another community member said, 'I have been applying for PIP for 7 years and never got it, and following [instructions of group moderators] to the letter, I have been awarded enhanced for both. Thank you [group moderators] you have changed my life I was about to give up.'

The appeals process further compounds difficulty. Many are initially denied PIP and must endure lengthy reconsiderations or tribunals, often at severe physical and emotional cost. Successful appeals expose flaws in the initial assessments, with claimants describing financial strain and health crashes during the process. These findings bring to the forefront that the mechanics of the UK’s benefits system for disabled people are not merely difficult to access for those with ME/CFS but are structurally misaligned with the nature of the illness itself. In this sense, the preceding analysis not only exemplifies a lived critique of welfare policy but also extends the logic of the social model, revealing how governmental systems convert bodily impairment into social disablement. Crucially, the rigid

operationalisation of disability within the welfare system mirrors the original limitations of the social model itself, particularly its emphasis on stable, visible and externally identifiable impairments. The benefits system relies on a fixed, observable conception of disability, failing to accommodate conditions that are fluctuating, invisible and medically contested. In doing so, it not only denies many people with ME/CFS the support they need but also reinforces social exclusion through bureaucratic processes that demand proof of suffering in forms that such conditions cannot reliably provide.

Millions Missing: Visual Protest and Relational Care

The *Millions Missing* campaign, mentioned 54 times during the netnographic data collection, is a global #MEAction initiative that raises awareness and demands political and medical justice for people with ME/CFS. It highlights both the physical absence caused by illness and the institutional invisibility created by decades of neglect and stigma. At its core, *Millions Missing* confronts the power structures of healthcare, welfare and public institutions through a striking visual campaign. Its posters use stark imagery and concise, emotive text to challenge dominant narratives around illness, disability and worth, directly exposing institutional neglect. As previously addressed, ME/CFS has long existed in the margins of biomedicine, often misclassified as psychosomatic, trivialised as fatigue, or rendered invisible by the lack of a diagnostic biomarker. These cultural and scientific exclusions translate into real-world consequences such as the absence of treatment options, lack of specialist services, and inaccessibility of disability benefits. The campaign posters explicitly highlight these failures and reframe them as structural violence. In doing so, they refuse the idea that the suffering of ME/CFS patients is an unfortunate medical anomaly, instead positioning it as a political outcome.

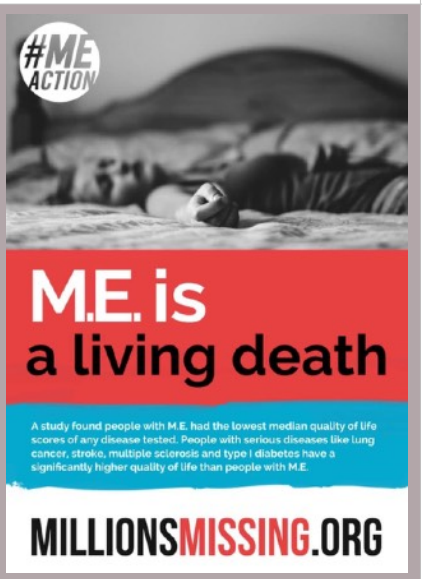
One of these posters, detailed in Figure 17, reads 'M.E. is we can’t help you. You’re on your own.' This poster depicts a doctor shrugging in front of a visibly distressed patient. The image communicates a withdrawal of care, a moment where the institution symbolised by the medical professional openly confesses its inadequacy. The accompanying text is not merely descriptive but accusatory, transforming the patient’s abandonment into a collective indictment. This image prompted a wave of testimonial storytelling in the forums it was shared in. In the comments, users recounted deeply personal experiences of medical dismissal: 'My doctor told me I know how to manage my illness better than he does, and he sent me away. I haven’t seen him since […] and that was 7 years ago.' Others echoed this structural abandonment, noting, 'There are no services at all available

in my area,' and 'My doctor said, ‘If I could help, I would, we just don’t have any tools to do that.'' These stories serve not only as validation but also as documentation, as they are citations of lived experience that collectively destabilise the myth of equitable healthcare provision.

Another poster detailed in Figure 18 reads, 'M.E. is untreatable due to decades of government neglect. In this poster, a child lies alone on a sofa, symbolising the profound isolation and precarity that ME/CFS patients experience, regardless of age. The innocence and vulnerability of the child sharpen the message that this is not a natural tragedy but a preventable injustice. The textual framing directly holds governments accountable, pointing to decades of underfunding and lack of institutional attention. Online engagement with this poster emphasised structural comparisons with better-funded diseases. One user wrote: 'They spend 25x more on MS research every year and you look at how treatment for that has improved […] and people didn’t believe that was real either, so imagine if they showed us that much interest, life could be so much better for us now.' Another comment drew attention to the political economy of illness: 'If the pharmaceutical companies can’t see a quick win where they can find a pill that fixes us all, then I can’t see any serious investment for a long time.' These reflections illustrate a critical public consciousness that sees the invisibility of ME/CFS not as accidental but as a byproduct of market-driven and bureaucratic health systems.

Another poster detailed in Figure 19 reads, 'M.E. is a living death.' This poster shows a woman lying motionless in bed, her lifeless posture rendering it ambiguous whether she is alive or dead. The phrase 'a living death' evokes the existential suspension endured by severe ME/CFS sufferers whose lives are defined by sensory deprivation, pain, and isolation. The image challenges cultural assumptions about what it means to be 'alive' and 'well,' questioning the values that underpin healthcare and disability assessments. In the comment threads, this image became a site of collective mourning, grief and perseverance. Some shared memories of friends with ME/CFS who had died. One commentator wrote, 'I met her in a forum and she was gone two years later. She never got the care she needed […] She was such a source of knowledge for us all and such a kind person.' Others testified to the ongoing emotional labour of survival: 'I would have given up, I honestly wouldn’t be alive if I hadn’t got this community to fight how shit they treat us.' Another poignantly noted: 'I just remind myself that there may one day be a better day, it doesn’t come, but just thinking that I might helps 😅🤣😂.' Others discussed grieving the

lives they used to inhabit, 'I sometimes find myself trying to do something like make some toast and I can't, and I remember oh yeah I can't do that for myself anymore, and it's just so sad' or 'I am another person now and I don't think I will ever know who I used to be again I feel like I am in this permanant state of grief for my lost self'. These comments reveal not only suffering but also resilience, solidarity, and a deep awareness of political and social structures.

Figure 17	Figure 18	Figure 19
		

What makes *Millions Missing* an interesting campaign is its dual function, as it serves both as an act of resistance and as a space of relational care. The posters themselves destabilise institutional narratives of inaction and challenge the gatekeeping of legitimacy in health discourse. Meanwhile, the online storytelling practices they inspire transform the ways in which illness is perceived, discussed, and responded to. The *Millions Missing* campaign invites us to rethink not only ME/CFS but also the broader cultural, economic, and political frameworks that determine who receives care and who is neglected.

It is useful to distinguish this form of activism from the imagery discussed in earlier chapters, which focused on destigmatising ME/CFS by making visible the physical realities of impairment. In contrast, the *Millions Missing* campaign situates blame and "horror" not in the impaired body but in the institutions that abandon it. This shift in emphasis represents a re-politicisation of the social model, and, rather than simply demanding recognition of suffering, the campaign redirects moral and political responsibility towards the state, foregrounding the structural violence of welfare policy and medical neglect. These findings

expose structural exclusion in the UK's benefits framework. PIP's rigid design misaligns with fluctuating, invisible conditions like ME/CFS, prioritising assessor impressions over expert evidence. Engaging with the process imposes disabling cognitive and physical strain, forcing claimants to perform their illness repeatedly in bureaucratic terms. The prevalence of successful appeals underscores systemic dysfunction and disbelief.

Facing institutional inadequacy, the digital community provides a strong counter-narrative. The ME/CFS benefits forum serves as an alternative care structure where knowledge is generated, shared, and refined. Moderators and members develop tools and provide strategic advice that translate ME/CFS experiences into benefits-assessment language. This often unrecognised effort reflects grassroots governance, offering practical guidance, emotional support, and validation. Furthermore, the Millions Missing campaign adds an outward dimension to this resistance. Through visual protest and storytelling, it redefines institutional neglect as a political choice rather than a medical necessity, challenging assumptions in healthcare and welfare systems and advocating for justice for a long-invisible population.

These insights must be considered alongside the UK government's 2025 proposal to restrict disability benefits, which would make PIP harder to qualify for (Department for Work and Pensions, 2025). This suggests a cruel worsening situation for disabled individuals (Hadi, 2025), especially those with ME/CFS, who already face increased exclusion risks. It underscores the need to redefine welfare as a right that accommodates the complexities of illness, rather than as a privilege based on performative legitimacy. Without this shift, the system will continue to harm those it claims to support.

Taken together, these findings make visible the enduring relevance, but also the limits of the social model of disability. While it remains vital for exposing how state institutions disable through bureaucratic and epistemic violence, the lived realities of ME/CFS suggest that any adequate framework must move beyond structural critique to encompass the embodied, fluctuating and relational dimensions of illness that the social model leaves unaddressed. The cumulative picture that emerges from these analyses, of contested embodiment, bureaucratic exhaustion, and political neglect, demands not only critique but reconstruction. If the social model exposes how society disables, and welfare policy demonstrates how disbelief is operationalised, what alternative frameworks might better sustain those whose capacities are unstable and whose legitimacy is routinely

questioned? The following section introduces one such proposal: a frailty-informed, relational model of care that not only makes absence politically visible but translates fluctuating, multisystem limitation into a governance-ready basis for coordinated care and stable entitlement.

Towards a Frailty-Informed, Relational Model of Care for ME/CFS

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Acknowledging that the findings of this study illustrate the harmful and insufficient nature of the current disability frameworks in the UK regarding (but by no means limited to) individuals with ME/CFS, it is essential to investigate new models/frameworks/approaches that effectively meet the needs and circumstances of those with ME/CFS and comparable illnesses. These frameworks must be founded on a radically different basis, one that dismisses the binary distinctions inherent in both the medical and social models and challenges the regimented structures of governance that have manifested in accordance with those models. As Shakespeare (2014) proposes, an interactional approach is required. Building on the theorists discussed, I suggest three interconnected principles: (1) fluctuation, recognising illness as episodic and unpredictable rather than linear; (2) relationality, locating disability within relationships among people, environments and institutions; and (3) frailty, acknowledging legitimacy without visibility and attending to the distinct embodied limitations of ME/CFS and related illnesses. For clarity, I will refer to these three principles as a *Frailty Model of Care.*

This proposed model aligns with broader traditions within feminist and relational ethics of care. Tronto (1993, 2013) conceptualises care as both a moral disposition and a political practice, structured around attentiveness, responsibility, competence, and responsiveness. These dimensions are echoed in the relational and fluctuating dynamics described by participants in this study. Similarly, Mol (2008), in *The Logic of Care,* emphasises that good care is not a one-off act but an ongoing process of collaborative efforts to build knowledge and tune technologies to uncertain and fluctuating bodies, an understanding that closely resonates with the lived reality of ME/CFS as expressed in this thesis's findings. By situating the frailty model within this broader literature, care is re-envisioned as a collective infrastructure rather than a private virtue; it is a distributed network of practices that sustain life amid vulnerability. Importantly, the frailty model proposed here does not reject the social model of disability. Instead, it extends and operationalises it for this population. Where the social model locates responsibility for disablement in social and institutional barriers, the frailty-informed approach translates that moral and political insight into concrete structures of care. It preserves the social model's emphasis on collective responsibility while providing clinicians and policymakers with practical mechanisms to sustain that responsibility amid fluctuating, embodied conditions such as ME/CFS.

What does the addition of frailty offer to a relational approach?

Frailty commonly refers to a syndrome that occurs in later life, which is characterised by pathologies such as weakness, slow motor performance, low physical activity, and a loss of resilience to rebound after illness or distress and 'includes a dynamic state of reduced physiological reserve, a diminished ability to perform the important practical and social activities of daily living, comorbidity, and multisystem decline' (Puts and Deeg, 2004, p. 40). However, frailty isn't reserved terminology for geriatric populations. Specifically looking at frailty and chronic illness, Önen et al.'s (2009) work with patients with HIV argued that it was clear that 'HIV infection was associated with a premature presentation of frailty' (p. 346). An investigation by Shuo Wang et al. (2023) explores frailty in breast cancer and bone marrow transplant survivors which they link to premature mortality, functional decline, and poor quality of life, and, additionally, research has also found that 'Young adult survivors of childhood cancer exhibit rates of frailty similar to adults several decades older without a cancer history' (Daniel et al., 2025, p. 1). Additionally, in her BJGP Life article, Dr Hausmann (2025) proposes that conditions like ME/CFS and Long Covid may be better understood as forms of premature frailty. Drawing from her experiences as a GP and a patient with Long Covid and POTS, she reflects on frailty as a 'loss of physiological reserve'. She questions how clinical care and policy might change if we acknowledged that younger individuals with chronic conditions experience similar vulnerabilities.

In this light, it is important to consider the underlying factors that constitute the term. When trying to define a research agenda towards a better understanding of the physiology and aetiology of frailty, Walston et al. (2006) evaluate the 'contributions of inflammatory, endocrine, skeletal muscle, and neurologic system changes' (p. 883) as factors that increase the severity of or indeed constitute the onset of frailty. Where their paper focused on geriatric research, there is a clear parallel with systems that are abnormal in patients with ME/CFS, who also exhibit abnormal inflammatory, mitochondrial, endocrine, skeletal, and neurological functioning. With this notion, the application of the term *frailty* as a descriptor becomes increasingly appropriate when considering symptomology and the restricted performance of those with ME/CFS.

In developing this framing, it is also important to situate the model within the reflexive and co-productive nature of this research. As disclosed earlier in the thesis, I live with ME/CFS, and my standpoint has inevitably informed the conceptual trajectory of this work. The *frailty*

model of care has therefore not emerged in isolation but through a dialogic exchange between researcher and community, shaped by shared epistemic and affective conditions. Across interviews, journals and forum data, participants repeatedly described experiences of physical precarity, multisystem instability and a loss of physiological reserve, using language that closely aligns with the semantics of frailty. Several also articulated a wish for their illness to be *visualised* as frailty so that their suffering might be rendered intelligible to clinicians and policymakers. In this sense, the adoption of the term is not an external imposition of medical discourse but a collective act of meaning-making, grounded in lived experience. The thesis, therefore, participates in the wider process of community-led knowledge generation and resistance, in which academic authorship becomes part of a shared labour of representation rather than a detached exercise in theorisation. In this context, the following section turns from the conceptual grounding of the *frailty* model to consider how such an approach might be operationalised in clinical and welfare practice, translating a co-produced idea into a pragmatic framework for care.

Operationalising a Frailty-Informed Model for ME/CFS

Framing ME/CFS within the existing understandings of frailty offers a transformative approach for both clinical practice and welfare provision. Frailty is already a well-established concept in UK healthcare, primarily used to describe older adults who experience vulnerability due to cumulative decline across multiple bodily systems. However, its principles, recognising systemic vulnerability, multisystem impairment, and fluctuating capacity, are highly applicable to those living with ME/CFS. Applying this model not only aligns ME/CFS with a respected clinical framework but also facilitates access to services, protections, and financial support systems currently available to those identified as frail. In clinical settings, frailty is seriously regarded as a diagnostic and management tool. It encourages proactive care planning, routine assessments, and integrated support across medical and social care teams. Individuals identified as moderately or severely frail often receive coordinated interventions such as home adaptations, community physiotherapy, occupational therapy, and regular GP-led care reviews. These are not merely medical considerations but represent structural and systemic responses to complexity and vulnerability.

Such systemic responsiveness echoes calls within feminist care ethics to re-embed social policy in the moral economy of care (Sevenhuijsen, 2003; Held, 2006; Barnes, 2012). These scholars emphasise that care must be recognised not only as emotional labour but

as a framework for justice, one that distributes responsibility across institutions rather than leaving it to individuals or families. Framing ME/CFS care through this lens repositions welfare and healthcare support as matters of shared social obligation rather than as matters of discretionary compassion. Translating this model to ME/CFS would entail embedding a similar level of responsiveness, recognising that these individuals, while often younger than the traditional frail elderly population, experience comparable levels of risk, impairment, and unpredictability.

Crucially, the idea of the frailty model accepts the premise that conditions can be both chronic and fluctuating, with episodes of partial recovery or decline. This is in stark contrast to the current benefits and healthcare approach to ME/CFS, which often fails to accommodate the relapsing-remitting nature of the illness. As discussed throughout this chapter, disability assessments are ill-equipped to handle fluctuation. They tend to demand consistency in either incapacity or capacity, thereby forcing individuals to underreport better days or risk losing vital support.

Frailty, on the other hand, does not require a person to be at their worst every day in order to be eligible for services or protections. This provides a powerful precedent for reform. The existing welfare framework for frailty also contains valuable parallels that could benefit ME/CFS sufferers. For instance, pensioners receive their state pension regardless of employment, allowing contribution to the work force, without penalty. Applying a similar principle within a frailty-informed model would enable people with ME/CFS to pursue flexible work without compromising essential support. This would acknowledge the real-life, episodic nature of ME/CFS and allow people to retain autonomy and dignity without being punished for temporary improvements[3].

Recent studies have highlighted that rather than returning to health levels prior to onset, most people with ME/CFS report a worsening of health and their symptoms (Tschopp et al., 2023). Supporting this call for a shift in approach is a significant recent finding from a Norwegian longitudinal study by Kielland and Liu (2025), which investigated the

[3] Although many UK disability benefits are means-tested, Personal Independence Payment (PIP) is not. The point made here about being “punished” for working refers instead to the PIP assessment process: netnographic data frequently indicated that claimants were denied qualifying points on the basis that they were in employment, notwithstanding the state’s framing of PIP as support intended to enable disabled people to enter or remain in work.

employment outcomes of 8,485 individuals diagnosed with G93.3 (the ICD code often used to denote ME/CFS). The study concluded:

> Very few appear to recover fully, and the overall trend during the AAP intervention period is one of deteriorating capabilities. Second, health and welfare providers must address this group with realism. Long, demanding intervention periods for persons diagnosed with G93.3 to determine their disability status may discourage and push out the most vulnerable from accessing rights-based public welfare benefits. Alternatively, it could prolong their ordeal rather than yield returns in terms of persons recovering to more work capacity. Third, there is a potential trade-off between interventions aimed at improving life quality and those investing in regaining income-earning capabilities (Kielland and Liu, 2025, p. 8).

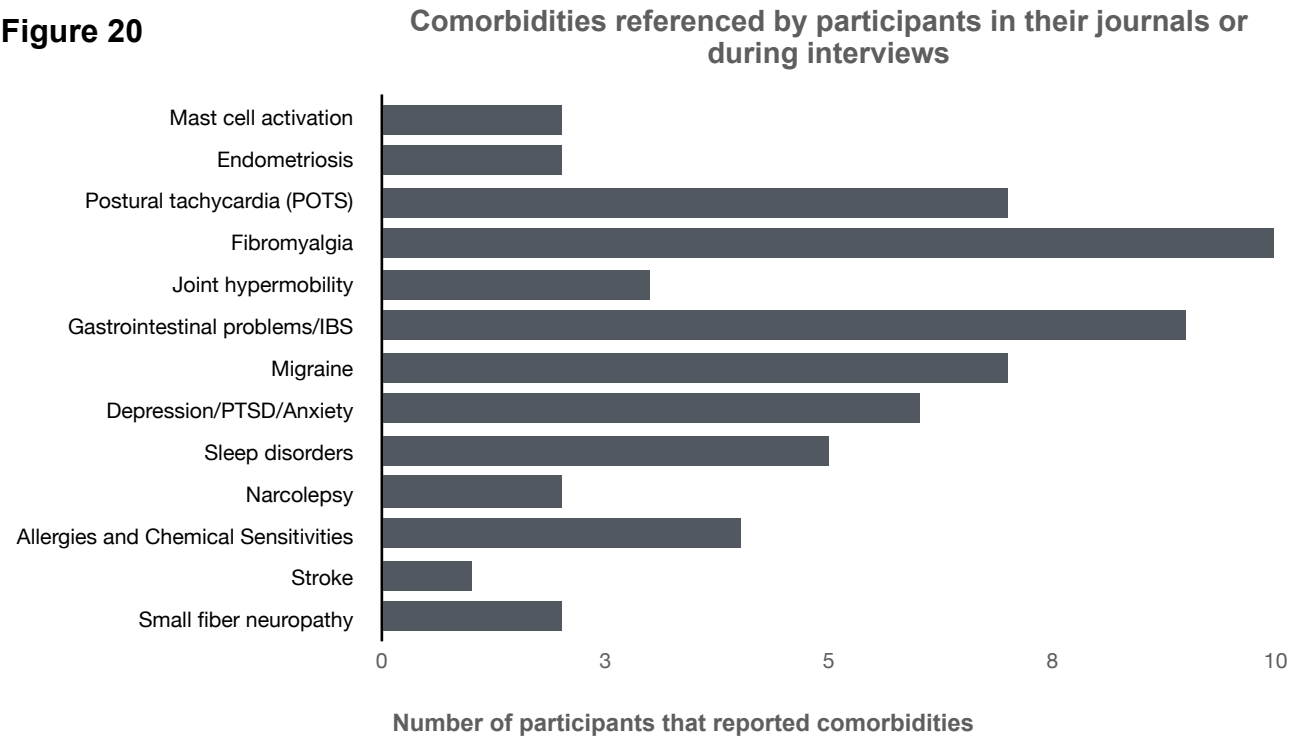
The findings from this study are highly relevant and cannot be overstated. They reveal a systemic flaw in how disability is assessed and supported: the assumption that extended interventions will yield a return in work capacity. For individuals with ME/CFS, this approach is not only ineffective but also often harmful.

As discussed earlier, expectation of eventual recovery or increased work participation often leads to prolonged assessment cycles, delayed support, and worsened health due to the stress and energy expenditure required to navigate the system. A frailty-based model would instead focus on stability, dignity, and quality of life, recognising that, for many, ME/CFS is a long-term and often permanent state of reduced function. Viewed through the lens of *suffering-capital* developed throughout this thesis, current disability governance converts the communicative labour of illness into a resource that primarily serves bureaucratic ends. Repeated assessments, work capability tests and form-filling require claimants to perform suffering in administratively legible ways, yet the value generated by this labour accrues largely to the state in the form of surveillance, gatekeeping and cost containment rather than to patients as security or care. A frailty model of care reorients this moral economy, instead of treating suffering as something to be doubted, tested and economised, it would treat the already-evident depletion of physiological and social reserves as sufficient grounds for stable entitlement, shifting *suffering-capital* from a currency of suspicion to one of guaranteed support.

Additionally, adopting a frailty approach would give clinicians a familiar framework easily integrated into existing protocols. Many are committed to helping but lack structured guidance for this complex condition. Framing ME/CFS in this way encourages a proactive approach to care, where doctors remain alert to the numerous comorbidities that often

accompany the illness so they can build in measures of review and assessment, much like they do for their older patients as standard protocol. For example, with frailty comes the risks of 'comorbidity, and multisystem decline' (Puts and Deeg, 2004, p. 40), indeed there is increasing literature on comorbidities with ME/CFS, such as mast cell activation, dysmenorrhea, endometriosis, postural tachycardia, small fiber neuropathy, fibromyalgia, joint hypermobility and gastrointestinal problems (Falaguera-Vera et al., 2020; Varesi et al., 2021; Wirth and Löhn, 2023; Mundie et al., 2024). Findings from interviews and journals supported this literature and highlighted a wide range of such comorbidities reported by participants (see Figure 23), many of which, such as POTS, narcolepsy, or cardiac irregularities, are serious conditions in their own right, and unlike ME/CFS, have clear treatment protocols. Left unrecognised, these comorbidities can be dangerous, can worsen the symptoms of ME/CFS and further reduce patients' quality of life.

Figure 20



Importantly, this is not about blaming clinicians but about equipping them with the right conceptual tools. Most doctors genuinely want to help but may unintentionally misattribute new or worsening symptoms solely to ME/CFS. In Chapter 4, it was highlighted that patients with ME/CFS often feel disbelieved by their doctors and fail to trust that they know a sufficient amount about the illness in order to administer appropriate care. The netnographic data also revealed this challenge as participants described having to 'battle

to get their doctor to run tests,' or how 'I had to bring in journal articles on POTS and shout to get tested.' Others shared experiences such as 'she kept telling me it was fatigue and then eventually two years later they're like, so yeah, it's narcolepsy,' or 'it wasn't until I was in A&E and they were monitoring my heart that the doctors there realised something was wrong and it wasn't just ME.' These stories highlight a systemic gap where the lack of a broader diagnostic framework leads to delayed or missed diagnoses. By viewing ME/CFS patients through the lens of frailty, clinicians could be encouraged to look beyond the surface, monitor for additional conditions, and intervene early. This benefits not only patients, who deserve timely and appropriate care, but also healthcare providers, who are better able to act with confidence and compassion if they have an existing procedure of maintenance that they can apply to this population. In this context, understanding ME/CFS as a form of frailty is not a label of weakness, but a clinical strategy for delivering safer, more effective care.

Risks and considerations when adopting a frailty framework

While framing ME/CFS through the lens of frailty offers a potentially transformative model for care, access to services, and benefit security, it is not without significant challenges. The concept of frailty carries cultural, emotional, and political implications that complicate its application to populations outside the elderly. Although frailty is an institutionalised and operationally effective construct within UK health and social systems, its use as a label, particularly for those with ME/CFS, can introduce new forms of stigma and resistance from both patients and healthcare professionals. One of the most well-documented issues surrounding the frailty label is the stigma associated with self-identifying or being identified as frail. Warmoth et al. (2015), in a qualitative study exploring older adults' experiences of frailty, found that many participants strongly resisted the label.

Goffman's (1963) foundational work on stigma offers a valuable lens for understanding these reactions. He describes stigma as a social process that transforms an individual from a 'whole and usual person to a tainted, discounted one' (p. 3). In *Asylums*, Goffman (1961) further conceptualises 'The mortification of self' (p. 19) as the systematic stripping away of identity through institutional practices that deny autonomy and redefine personhood according to bureaucratic categories. Applied to the context of frailty and ME/CFS, the assignment of such labels can function as a form of symbolic mortification, replacing self-authored identities with medicalised ones. The labelling of an individual as frail or chronically fatigued often invites a script of dependency and loss, narrowing the

possibilities of self-representation. Conversely, as Goffman notes (1963, p. 75), stigma management and ‘passing’ are forms of resistance through which individuals attempt to preserve a coherent sense of self in the face of discreditation. The resistance of both older adults and ME/CFS participants to the frailty label can thus be read as an attempt to avoid this institutionalised mortification and to maintain agency over the terms through which their bodies and capacities are recognised.

While recognising their own physical limitations, individuals expressed concern about the negative connotations of frailty, associating it with dependency, decline, and social irrelevance. This self-labelling dilemma often led to emotional distress and reluctance to engage with medical support, even when it was clearly needed. The study concluded that older adults often experience stigmatisation similar to that of other marginalised groups, not because of their condition itself, but because of the social meanings attached to it.

This problem is mirrored in the ME/CFS community. During interviews conducted for this research, one participant, despite clearly describing objective, severe limitations to her physical functioning, stated, 'I wouldn’t say that I suffer because of it. I am very lucky to have very supportive and understanding family and friends, who do know my reality of living with M.E' (Participant L). Her use of language suggests an internal negotiation between the reality of illness and the desire not to be seen as a victim or a burden. Earlier discussions in this Chapter on disability pride and disability shame shed light on this issue. Many individuals with ME/CFS do not wish to be perceived as helpless, passive, or non-contributing. They want to retain an identity grounded in agency, resilience, and work ethic. The frailty label, however well-intentioned in its clinical application, risks undermining this identity by pathologising individuals in ways they find emotionally or socially unacceptable.

The discomfort with the term is not limited to patients. Archibald et al. (2020) found that clinicians often avoid using ‘frailty’ for fear of harming rapport, leading to avoidance even when assessments are appropriate. This reluctance, while protective in intent, can inadvertently lead to missed opportunities for honest conversations about needs, care planning, and long-term support. If applied to ME/CFS, this tension could become even more pronounced. Given the historical mistrust between patients with ME/CFS and the medical establishment, rooted in decades of scepticism and dismissal, introducing a new but potentially stigmatising term may create further barriers rather than open doors.

However, there may also be scope for a partial reclaiming of the term, akin to the linguistic and political reclamations achieved within other marginalised movements. Like the reclamations of “queer” (Jagose, 1996) and “crip” (McRuer, 2006), “frail” could be re-inscribed to emphasise interdependence and care as strengths. Re-appropriating its medical currency would allow patients to subvert biomedical authority, asserting that frailty warrants structural care rather than signifying worthlessness.

Beyond individual interactions, there are broader structural and political criticisms of the frailty framework. Tomkow (2018) provides a particularly compelling critique, arguing that frailty has evolved into a biopolitical discourse within the UK healthcare system. In this view, frailty is no longer merely a clinical descriptor but a category through which resources are allocated and populations are governed. According to Tomkow, 'In these narratives, the meaning of frailty is subverted; instead of a frail population being inherently vulnerable and in need of protection, it is considered a threat to health-care systems due to the mismatch between frail individuals’ multifaceted health issues and the more binary approach to medical treatment offered by health service providers' (Tomkow, 2018, p. 706). This means that while frailty is meant to identify those in need, it simultaneously becomes a marker of economic inefficiency or institutional burden. As Tomkow further notes, 'Whilst a frail individual is liable to fail, and so requires protection, the process of being offered such protection makes them both an economic risk and a burden to the current configuration of health care' (p. 706). This duality, being protected and problematised, poses a risk when considering the application of the model to ME/CFS. Patients who already experience systemic neglect may find that a frailty classification legitimises their needs but also frames them as costly and unproductive, reinforcing negative societal attitudes rather than challenging them.

Furthermore, even within the established frailty protocols, implementation is far from seamless. Faulkner et al. (2024), in their study of community pharmacists’ confidence in managing frail patients, found that many health professionals felt poorly equipped to deliver comprehensive care. Despite the availability of guidelines and tools, pharmacists reported fragmented service structures, unclear responsibilities, and insufficient interdisciplinary communication. This raises an important question: even if ME/CFS patients were included within the frailty framework, would the system be able to respond meaningfully to their needs? The mere existence of a framework does not ensure its effectiveness, particularly when resources, training, and coordination remain limited.

These concerns are valid and must not be overlooked. Frailty, like ME/CFS, is not merely a medical condition; it is a social category laden with assumptions about worth, productivity, and dependence. Placing disability pride and shame within this chapter clarifies that governance is felt as much as it is administered; eligibility is an affective as well as a legal category. For patients who already feel marginalised, adopting a term that may reinforce these narratives could be profoundly alienating and doom-laden. Indeed, Shakespeare warns us 'that impairment and illness should not be regarded as the end of the world, tragic and pathological' (Shakespeare, 2014, p. 84).

From the perspective of the moral economies of visibility discussed in Chapters 1 and 2, such labelling decisions do not operate only at the level of self-concept but also at the level of how suffering circulates and is valued. To call someone “frail” is to position them within pre-existing regimes of *suffering-capital* in which some forms of dependency are treated as deserving of care and others as wasteful or excessive. For a population who have had to fight for any recognition at all, the risk is that frailty functions less as a protective category and more as another filter through which their claims can be discounted. Furthermore, professionals’ discomfort with the term and the politicised nature of its application could undermine the very benefits it is intended to deliver.

While the social model remains the ethical cornerstone of disability politics, the frailty framework can serve as its pragmatic companion. A means of embedding those politics within health and welfare infrastructures rather than a departure from them. As such, the frailty framework should not be hastily dismissed, as it is also a socially and institutionally accepted construct. Still, much like ME/CFS, it carries its own stigma, and the label may understandably pose challenges for many patients. If we can shift away from the label and concentrate on the principles that this framing offers, such as structured and integrated care, recognition of multisystem complexity, and pathways to existing services, then it deserves serious consideration. It may currently be the most effective tool to enhance access to services and utilise existing governance frameworks that are presently failing this population. This potential is underscored by the findings of Kielland and Liu (2025), who found that 'very few appear to recover fully, and the overall trend during the AAP intervention period is one of deteriorating capabilities' (Kielland and Liu, 2025, p. 8). Moreover, they concluded that,

> long, demanding intervention periods for persons diagnosed with G93.3 to determine their disability status may discourage and push out the most vulnerable from accessing rights-based public welfare benefits. Alternatively, it could prolong their ordeal rather than yield returns in terms of persons recovering to more work capacity (Kielland and Liu, 2025, p. 8).

These findings directly challenge the dominant narrative that long-term assessment and conditional support encourage recovery. In reality, they highlight the need for a model that recognises chronicity and prioritises stability over productivity, a model that frailty, if properly adapted, could offer.

While the label 'frailty' may be uncomfortable and even counterproductive for some, the framework it represents holds significant clinical and structural advantages. What is needed is a reframing, not of patients, but of the system's approach. If we can retain the therapeutic, inclusive and socially reflexive progressive interpretations of the social model, with the practical benefits of incorporating systemic understandings of frailty, such as coordinated care, recognition of fluctuating conditions, and access to multidisciplinary support, while discarding its limiting and stigmatising language, we could establish a more inclusive and effective model of care for people with ME/CFS. It would also acknowledge the long-term and often permanent nature of the illness, as highlighted in the Kielland and Liu (2025) study. By recognising that most individuals with ME/CFS do not recover in ways that enable them to return to full employment, systems could shift away from pressure-based recovery narratives and towards compassionate, realistic support.

Nevertheless, the adoption of any medicalised vocabulary carries inherent risks. As the previous chapter's discussion of linguistic sovereignty demonstrated, when patient communities surrender terminological control to institutional frameworks, they risk reinscribing the very hierarchies they seek to dismantle. Using *frailty* within official discourse may offer pragmatic gains, yet it also recentres medical epistemology as the primary arbiter of legitimacy. This reproduces the binary between *abled/disabled* and *well/unwell* that ME/CFS experiences fundamentally unsettle. A more radical alternative would be to allow the community's own fluid, plural vocabularies, those that circulate through forums, MEpedia, and patient writing, to inform future frameworks of care. Such a model would not translate lay terms into professional jargon but would recognise them as epistemically valid in their own right. This proposal also sits within the *pharmakon* logic that underpins the earlier discussion of mediation. Just as digital platforms can both exploit and sustain disabled communities, frailty as a framework can either entrench paternalism

or provide a vehicle for co-authored care. A genuinely frailty-informed model of care for ME/CFS would therefore need to be developed with, rather than for, the digital publics and patient collectives who already practise forms of mutual care and expertise online, treating their communicative labour and experiential knowledges as central design resources rather than peripheral “lived experience” add-ons. Doing so would extend the notion of linguistic sovereignty from the cultural sphere into governance, enabling welfare and healthcare systems to evolve toward genuinely dialogic, co-authored forms of support.

Ultimately, the UK does not need to construct an entirely new system to serve those living with ME/CFS. Frailty offers an institutionally recognised set of tools, pathways and assumptions, such as coordinated care, attention to multisystem complexity, acknowledgement of fluctuating capacity, and a presumption of vulnerability. These could be adapted to this population. Such an approach would not resolve the political struggle for legitimacy, but it could provide a pragmatic route to more stable support and more coherent clinical responses, particularly if developed with patient collectives and digital publics as co-authors rather than treated as a purely professional framework. Adopting this model for ME/CFS is not merely a theoretical proposal; it is a practical, quickly actionable pathway for improving care and securing social justice for a marginalised group. The research is clear, the systems are in place to provide more considered and attentive care for this population, and the urgency is undeniable. What remains is the will to apply this existing framework where it is so clearly needed.

Summary

This chapter has examined how people with ME/CFS navigate the social, political and emotional systems that shape disability and chronic illness. It shows that pride and shame are not private feelings but social responses to institutional demands for proof, productivity and consistency. Pride emerges through solidarity, storytelling and resistance, while shame arises from disbelief, welfare bureaucracy and expectations of self-sufficiency. These findings reveal that governance operates through emotion as much as policy, influencing how disabled people see themselves and are seen by others.

The discussion has both challenged and extended the social model of disability. It supports the model's central claim that structural barriers disable, while exposing its limits for energy-limiting, fluctuating conditions. For many participants, the model failed to account for bodily exhaustion, pain and instability. Yet the community also reclaimed it as a political tool to locate responsibility within social and governmental systems. Through digital activism and visual protest, people with ME/CFS demonstrated that the social model remains relevant when expanded to recognise embodied constraint as part of disablement.

The chapter also highlighted how the welfare system, particularly the UK benefits framework, turns illness into administrative labour. Rigid assessments and disbelief convert fluctuating impairments into exclusion. In response, online communities have built informal infrastructures of care and expertise where collective knowledge and emotional support replace institutional failure, enacting the principles of care that formal systems neglect.

Finally, the chapter proposed a frailty-informed, relational model of care. Building on the social model's focus on systemic responsibility, this approach recognises fluctuation, interdependence and legitimate vulnerability as central to chronic illness. It reframes care as a shared social obligation rather than a conditional benefit and reinterprets frailty as a state requiring cooperation rather than denoting weakness. In doing so, the chapter contributes a new framework for understanding and supporting chronic illness through systems grounded in stability, dignity and collective care.

CHAPTER 7: CONCLUSION

Introduction

This concluding chapter draws together the empirical and theoretical strands of the thesis to show how people with ME/CFS use digital landscapes not only to endure neglect, but to re-make the terms on which their illness is known, governed, and cared for. The project began with four core aims:

1. To examine how people with ME/CFS communicate suffering online;
2. To analyse how these practices shape identity, community, and epistemic/ biopolitical capital.
3. To explain how they interact with, resist, or reproduce wider fields of power.
4. To contribute to theory on suffering, care, disability, and media power.

These aims reflect the longitudinal, qualitative design of the study and its central concern with how micro-level communicative practices are entangled with macro-level structures of legitimacy, governance, and care.

Guided by these aims, the thesis addressed four research questions:

1. How do people with ME/CFS communicate and mediate their suffering through digital environments?
2. In what ways do these practices generate identity, community, and epistemic or biopolitical capital?
3. How do digital practices position sufferers within wider fields of power and regimes of suffering?
4. How do people with ME/CFS seek to depoliticise or repoliticise their suffering online, and what if any are the implications of this for recognition and care?

Taken together, these questions have structured the movement of the thesis from lived experience and online interaction, through collective knowledge-making, to welfare, policy, and proposals for a different model of care.

Chapters 1 and 2 established the empirical and conceptual terrain. They situated ME/CFS as an illness marked by contested legitimacy, diagnostic uncertainty, and longstanding biomedical neglect, while positioning digital media as a pharmakon: a set of infrastructures that can both support and exploit those seeking information, solidarity, and recognition. Drawing on Bourdieu, feminist ethics of care, disability studies, and media theory, these chapters developed the conceptual vocabulary of *habitus, suffering-capital*, and digital *pharmakon* that underpins the subsequent analysis. Chapter 3 set out the methodological framework: a critical–interpretivist, longitudinal design combining netnography, participant journals, and interviews, grounded in reflexive engagement with the author's own lived experience of ME/CFS. In doing so, it traced how digital networks also operate as informal laboratories in which treatment protocols are collectively curated, evaluated and circulated, expanding the field of patient expertise beyond traditional medical boundaries.

Chapters 4 and 5 addressed the first two research questions by examining how sufferers communicate and mediate their condition online, and how these practices generate identity, community, and epistemic/biopolitical capital. Chapter 4 traced the creation of patient-led healthcare protocols around supplements, pacing, heart-rate monitoring, vagus nerve stimulation, off-label pharmaceuticals, and vaccination decisions. It showed how digital environments enable people with ME/CFS to convert embodied suffering into practical know-how and collective experimentation, while remaining exposed to quackery, misinformation, and the toxic potentials of self-experimentation. Chapter 5 extended this analysis to the infrastructures that stabilise and circulate this knowledge: MEpedia, charity blogs, biobanks and genetic studies such as DecodeME, patient lexicons, visual campaigns, and influencer labour. It theorised these practices as evidence of a *political–biosocial habitus* in which suffering capital is systematically transformed into epistemic and symbolic capital, reconfiguring who is authorised to define credible knowledge and representation.

Alongside these communicative and representational practices, participants also engaged in the collaborative curation of treatment knowledge. Across forums, blogs and MEpedia entries, community members collected, translated and compared biomedical research, experimenting with pacing tools, supplement regimes and symptom-tracking devices. These exchanges did not simply fill a gap left by medical neglect; they constituted an emergent form of lay biomedicine in which experiential and scientific knowledge were woven together through digital collaboration. In this sense, the digital landscape functions

as both a site of care and a decentralised laboratory, where treatment ideas are tested, revised, and ethically debated in real time.

Chapter 6 turned to the third and fourth research questions, analysing how these communicative and epistemic practices position people with ME/CFS within broader fields of power and regimes of suffering. It examined the emotional politics of disability pride and shame, showing how feelings of legitimacy and embarrassment are patterned by welfare systems that demand proof, productivity, and consistency rather than by individual fragility. It then critiqued the limits of the social model of disability for energy-limiting, fluctuating conditions, before analysing how people with ME/CFS navigate the UK benefits system and participate in campaigns such as *Millions Missing*. These welfare and protest arenas revealed how the state mechanises disbelief, how patients construct alternative infrastructures of care and expertise, and how suffering is continually repoliticised through visual and narrative practices. The chapter concluded by proposing a frailty-informed, relational model of care that draws on existing frailty frameworks, feminist ethics of care, and the thesis's own findings to sketch a more adequate basis for clinical practice and welfare policy.

The next sections clarify the thesis's original contributions to theory, methodology, and practice; articulate the policy and clinical implications of a frailty-informed, relational model of care; and outline directions for future research. In doing so, the chapter argues that ME/CFS, as traced through digital life, is not only a case of biomedical neglect but a lens through which to rethink the politics of suffering, care, and media power in contemporary societies.

Theoretical Contributions

This thesis contributes new theoretical tools for understanding how suffering, care, and legitimacy are mediated within digital and institutional systems. It extends established frameworks in sociology and disability studies by reworking Bourdieu's conceptual apparatus, advancing a relational and phenomenological understanding of disablement, and proposing a frailty-informed model of care that bridges theory and practice. Together, these contributions offer a reorientation of how chronic illness is theorised, locating it not only within biomedical or social structures but within communicative, affective and digital economies.

Suffering-Capital and the Moral Economies of Visibility

A central theoretical contribution of this thesis is the concept of *suffering-capital*. Building on Bourdieu's (1984, 1986) theorisation of capital as convertible forms of power within social fields, *suffering-capital* names the ways that embodied affliction, when mediated and made visible, becomes a form of social currency that can both confer and withdraw legitimacy. *Suffering-capital* captures how visibility, lived experience, and social recognition are interdependent, and how the circulation of suffering through media and bureaucratic systems defines whose pain is accepted, believed, or dismissed.

For people with ME/CFS *suffering-capital* is often precarious. Because the illness is invisible, fluctuating, and medically contested, the labour required to make suffering legible becomes an ongoing demand. The analysis throughout this thesis demonstrates how digital environments provide both opportunities and pressures for that visibility. Online platforms allow sufferers to communicate the nuances of post-exertional malaise, cognitive fog, or sensory hypersensitivity, translating embodied experience into textual and visual testimony. Yet visibility comes at a cost. As participants described, to be seen as legitimate often required the repetition of distress, self-disclosure, and proof of debility. This cycle of display and doubt turns suffering into a form of capital that must be continually renewed within moral economies shaped by neoliberal and biomedical expectations.

Suffering-capital, therefore, extends Bourdieu's framework in two ways. First, it makes visible a field where legitimacy is not only achieved through education, class, or taste, but through the mediation of bodily experience and affect. Second, it introduces an explicitly communicative dimension: capital here is not only embodied but broadcast, negotiated

through the infrastructures of media, bureaucracy and activism. This foregrounds how the moral value of suffering is shaped by visibility politics. The thesis shows that visibility is never neutral; it is administratively, emotionally, and politically negotiated. In welfare systems, claimants are compelled to perform suffering in bureaucratically acceptable ways. In digital communities, visibility becomes a means of solidarity and resistance. In both, visibility functions as a gatekeeper of care.

By theorising suffering as both an epistemic resource and a target of bureaucratic suspicion, this thesis contributes a new vocabulary for understanding affective governance in chronic illness. *Suffering-capital*, therefore, becomes a critical tool for engaging with the mediation of suffering itself. It reveals how moral economies of visibility structure who is recognised as a credible subject of care and who remains invisible, and how digital practices both contest and reproduce those hierarchies.

The Political–Biosocial Habitus

The second theoretical contribution is the development of the *political–biosocial habitus*. Drawing on Bourdieu's (1977, 1990) concepts of field, *habitus* and capital, this framework extends his sociological theory into digital and biosocial contexts. The *political–biosocial habitus* describes the shared dispositions, knowledges and practices that emerge when individuals collectively navigate illness, stigma and institutional neglect through networked environments. It is both digital and embodied, structured through the material constraints of the body and the affordances of online platforms.

Unlike Bourdieu's original conception of *habitus* as largely unconscious and socially inherited, the *political–biosocial habitus* identified in this thesis is deliberately generated. Within ME/CFS communities, participants engage in sustained boundary work that defines who counts as credible, what forms of knowledge are legitimate, and how illness should be represented. This reflexive labour is visible in the creation of diagnostic lexicons, MEpedia entries, image archives and advocacy campaigns. Rather than reproducing a pre-existing structure, the community collectively builds one, teaching each other how to inhabit it. *Habitus* here becomes not only a set of dispositions but a pedagogical project, consciously cultivated in response to epistemic injustice.

The *political–biosocial habitus* is therefore collective, digital, affective and epistemic. It operates through acts of solidarity, mutual verification and patient-led research, but also

through frustration, distrust and fatigue. It produces new forms of cultural labour in which patients curate, interpret and legitimise biomedical information. This *habitus* mediates between body and platform, translating physiological experience into digital discourse. It converts *suffering-capital* into epistemic and symbolic capital, reconfiguring who counts as an expert within the field of health knowledge.

This concept extends Bourdieu's framework by demonstrating that *habitus* can also be a conscious, strategic, and co-produced formation. In digital illness cultures, *habitus* is dynamically negotiated through networked exchange and collective reflexivity. The *political–biosocial habitus*, therefore, captures how chronic illness reshapes the field of health knowledge through participatory infrastructures. It links embodied experience with digital participation and political consciousness, revealing how the digital reorders the relations between knowledge, care and power.

Extending the Social Model: From Structural Barriers to Embodied Limits

A further theoretical contribution lies in extending the social model of disability to account for fluctuating, energy-limiting conditions such as ME/CFS. The social model remains a cornerstone of disability studies and activism, asserting that people are disabled by social and structural barriers rather than by impairments themselves (Oliver, 1990). This thesis affirms the continuing political and ethical importance of that claim, while also exposing its conceptual limits for illnesses characterised by instability, invisibility and medical contestation.

Participants' narratives demonstrate that while social and environmental barriers exacerbate exclusion, the material realities of ME/CFS, such as post-exertional malaise, sensory overload, and severe fatigue, cannot be entirely mitigated through accessibility or attitudinal change. As several participants remarked, no number of adjustments can remove the physical impossibility of sustained participation. For these individuals, disablement is both socially and biologically constituted. This thesis, therefore, argues for an interactional and relational understanding of disability that integrates bodily constraint within the analysis of social power.

By embedding phenomenological attention to the lived body within sociological critique, this extension moves beyond the binary of the medical and social models. It draws on scholars such as Crow (1992), Wendell (1997), Carel (2016, 2018) and Shakespeare

(2014) to affirm that impairment, pain, and exhaustion are not merely personal tragedies but real, embodied conditions that interact with social systems in complex ways. In the context of ME/CFS, this intersectionality is heightened by the requirement to constantly prove legitimacy to both clinicians and bureaucrats.

The thesis, therefore, contributes to disability theory by embedding the phenomenological and fluctuating body within the political analysis of disablement. It proposes that chronic illness demands a theoretical vocabulary that can hold together suffering and structure, biology and bureaucracy. This approach enables disability studies to better account for the lived temporalities of fatigue, relapse and uncertainty, and for the affective economies that shape disabled identities under neoliberal governance.

Frailty as Co-Produced Framework

The final theoretical contribution is the development of a *frailty-informed relational model of care*, which reinterprets frailty as a relational and political condition rather than a marker of decline. This framework emerged directly from the empirical findings and from dialogue with participants, making it a co-produced conceptual innovation. It bridges feminist and relational ethics of care (Tronto, 1993, 2013; Mol, 2008; Held, 2006) with digital sociology and disability studies, transforming the moral and affective insights of the social model into a practical structure for policy and healthcare reform.

Frailty, in this thesis, is not restricted to older age but is understood as a state of reduced physiological reserve that can affect younger individuals with chronic illness. For people with ME/CFS, who experience multisystem dysfunction, unpredictability and physical vulnerability, the concept of frailty provides both clinical traction and moral recognition. By aligning ME/CFS with an established medical framework that already commands institutional attention, this model offers a route to improved care coordination and welfare stability.

Importantly, this framework does not reject the social model but operationalises its principles. It translates the moral claim - that society disables - into concrete mechanisms of responsibility and argues for proactive care planning, flexible eligibility for support, and integrated pathways across health and welfare. At the same time, it incorporates the relational ethics of care, situating care as an ongoing collective practice rather than a one-off intervention.

However, as discussed in Chapter 6, the frailty framework is not without risk. The term carries cultural stigma and can reproduce narratives of dependency or decline. The thesis therefore reframes frailty as a shared social condition that reveals interdependence, not weakness. Like the reclamations of other marginalised identities (McRuer, 2006; Jagose, 1996), frailty can be re-signified as a politics of care and solidarity. This reframing resists the neoliberal conflation of value with productivity, repositioning dependence and vulnerability as relational strengths.

By reinterpreting frailty as a relational and political condition rather than a marker of decline, this framework offers an actionable model for policy and healthcare reform. It provides a vocabulary for integrating the fluctuating, embodied realities of chronic illness into the design of social and clinical systems, and it extends the participatory ethos of digital disability cultures into formal governance. The frailty-informed model, therefore, constitutes both a theoretical and practical contribution: a means of re-embedding care within the moral and institutional economies of contemporary society.

Together, these four contributions (i) *suffering-capita*l, (ii) the *political–biosocial habitus*, (iii) the extension of the social model, and (iv) the frailty-informed relational framework form the theoretical core of the thesis. Each demonstrates how the lived and digital experiences of people with ME/CFS invite a rethinking of key sociological and disability concepts, from capital and habitus to visibility, care and legitimacy. In doing so, the thesis provides an integrated account of how suffering becomes meaningful, how care becomes political, and how digital life reshapes the possibilities of both.

Methodological and Reflexive Contributions

This study contributes to qualitative and digital methodologies by developing a reflexive, care-informed approach to researching chronic illness within digital environments. Its design combines digital ethnography, textual and visual analysis, and participant co-production, forming a framework that not only safeguards participants' well-being but also expands what kinds of knowledge can be captured from communities living with energy-limiting conditions. The approach was grounded in the principles of attentiveness, reciprocity and situated knowledge, ensuring that the study's ethical and epistemological foundations were aligned.

Digital and Netnographic Methodology

The study's first methodological contribution lies in its adaptation of digital ethnography to an illness context defined by limited energy, fluctuating cognition and institutional neglect. Digital spaces are not merely supplementary for people with ME/CFS; they are the central arenas where identity, knowledge and solidarity are constructed. A netnographic approach was therefore adopted, incorporating observation of online forums, social media campaigns, patient-led archives and advocacy materials. This method captured the everyday practices through which participants exchange care, create legitimacy and resist disbelief, while also tracing how online infrastructures sustain a collective epistemic culture.

The methodological innovation rests on combining ethnographic immersion with textual and visual analysis, allowing illness narratives, memes, and digital artefacts to be studied as relational performances rather than static texts. Visual materials such as campaign posters and memes were examined as acts of cultural production that communicate both affect and argument. Textual materials were analysed to trace how knowledge is collaboratively built, debated and circulated. This integration of modalities allowed the researcher to account for the multimodal ways in which people with ME/CFS express and make sense of illness.

Crucially, the longitudinal and multimethod design enabled data collection that would have been difficult, if not impossible, through conventional approaches. People with ME/CFS often experience cognitive dysfunction, sensory sensitivity and severe fatigue that make structured interviews or focus groups inaccessible. Expecting concise or balanced

answers in a single sitting from participants experiencing brain fog is unrealistic and risks reproducing the very epistemic exclusions the study seeks to address. The flexible, layered design of this project countered those barriers. It combined asynchronous interviews, participant journals and extended netnography, allowing participants to contribute in their own time and in ways compatible with fluctuating capacity.

This methodological flexibility generated forms of data that were both richer and more authentic than conventional one-off encounters. Journals provided space for slow reflection, capturing experiences that participants might have struggled to articulate verbally. Netnography, meanwhile, preserved the naturalistic rhythms of online interaction, revealing the spontaneous exchanges and collective sense-making that occur outside formal research settings. Taken together, these methods expanded the representational range of qualitative inquiry, giving voice to individuals whose participation in traditional studies is often curtailed by the physical and cognitive demands of research itself.

Ethical engagement was embedded throughout as a process of relational care rather than procedural compliance. Online participants were anonymised and paraphrased where appropriate, and direct communication was shaped by sensitivity to cognitive load, fatigue and emotional labour. The project followed the ethical logics of feminist and disability scholarship (Tronto, 1993, 2013; Mol, 2008), recognising that attentiveness and responsibility are as integral to rigour as methodical consistency. This approach treated ethics not as a constraint on research but as a mode of access: by designing methods around care, the research reached individuals and experiences that would otherwise remain undocumented.

Reflexivity and Situated Knowledge

The second methodological contribution concerns reflexivity and positionality. As discussed in Chapter 3, this study was conducted by a researcher living with ME/CFS. Rather than being treated as a source of bias, this positionality was recognised as an analytic resource that enabled deeper engagement with the field. Living with the condition provided embodied insight into phenomena such as post-exertional malaise, sensory overload and the emotional labour of disbelief. These experiences informed not only interpretation but also the design of the research itself, helping to anticipate participant needs, adjust pacing, and structure communication in accessible ways.

This reflexive awareness shaped both access and analysis. Being part of the community, even peripherally, helped establish trust and legitimacy, encouraging participation from individuals who are often sceptical of academic research due to past misrepresentation. At the same time, systematic documentation, iterative coding and theoretical framing maintained analytic distance. The result was an insider–outsider dynamic that moved between empathy and critique, enabling data interpretation that was emotionally attuned yet intellectually rigorous.

Reflexivity also operated as a practical ethic of care. Managing energy limits, scheduling fieldwork around fluctuations, and allowing for recovery were not only personal necessities but reflections of the very realities being studied. These practices became a structural feature of the methodology: research was paced, not rushed; conversation was asynchronous, not extractive. In this way, the project enacted the same principles of adaptation and accommodation that participants used to navigate their own lives.

This reflexive, accessible model enabled a more inclusive and accurate representation of community voices. It acknowledged that insight arises not only from what participants say but from how, when and under what conditions they are able to say it. By creating multiple avenues for contribution (journals, asynchronous interviews, netnographic observation), the research captured experiences across a spectrum of illness severity, including those who are largely housebound or bedbound and seldom visible in public discourse.

The result is a methodological framework that expands what counts as viable qualitative data and who counts as a viable participant. It shows that flexibility, care and researcher embodiment are not weaknesses but conditions of access that allow hidden forms of knowledge to surface. This model is transferable to other studies of chronic illness or disability where cognitive or physical constraints affect participation. By integrating care, pacing and co-production into research design, future projects can align methodological practice with the lived ethics of the communities they seek to understand.

This study, therefore, demonstrates that reflexivity, when embedded from the outset, can be both an ethical stance and an epistemic method. It produces richer, more inclusive data by recognising that knowledge is always situated in bodies, relations and capacities. Reflexivity, in this sense, is not an afterthought or a disclaimer but a central mode of knowledge production, one that makes visible what more conventional methods overlook.

Policy and Practical Implications

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The findings of this thesis reveal that the everyday realities of people with ME/CFS are shaped by the interplay of policy, governance and culture as much as by biology. Disbelief, bureaucratic exclusion and institutional neglect are not isolated failures but embedded features of existing systems. Yet, across digital spaces, people with ME/CFS have collectively generated a remarkable body of data, interpretation and advocacy. This constitutes what might be described as a *shadow knowledge economy*: an informal but highly organised system of patient-led evidence, expertise and care that operates in the absence of institutional responsiveness (see below). The challenge for policymakers is not only to reform dysfunctional structures but to recognise and integrate the epistemic labour already being carried out within these communities.

Welfare and Governance

The welfare findings demonstrate that the UK's benefits system continues to disable by design. Programmes such as Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) rely on rigid, binary criteria that cannot capture the fluctuating, invisible and multisystemic nature of ME/CFS. Claimants are compelled to narrate suffering in administratively legible forms, performing illness as paperwork. The emotional and physical cost of this process constitutes a form of state-sanctioned exhaustion.

Reform should begin with a recognition of fluctuation as an inherent condition, not an anomaly. Eligibility systems must move from static to dynamic assessment models, where temporary improvements or deteriorations can be reported without triggering punitive reassessments. Regular, light-touch reviews co-produced with claimants could replace exhaustive cycles of form-filling and appeal.

Assessment itself must also be restructured. The study revealed widespread frustration with assessors' lack of clinical knowledge, particularly around post-exertional malaise and fluctuating impairment. A co-produced model in which medical practitioners with relevant expertise, claimants, and trained patient advocates collaboratively review evidence would be more just, transparent, and cost-effective.

Crucially, the government should formally recognise the informal infrastructures of expertise already thriving in patient networks. Online benefits forums function as community-run advisory systems, sharing legal guidance, appeal templates and emotional support. Incorporating such community representatives into consultative panels within the Department for Work and Pensions (DWP) would legitimise lived expertise as a form of policy knowledge. This would not only improve outcomes but help rebuild trust between disabled citizens and the state.

Healthcare and Clinical Practice

The health system's failure to adequately diagnose, treat and support people with ME/CFS mirrors the same epistemic biases evident in welfare. Clinical neglect is sustained by a lack of diagnostic clarity, the absence of integrated care, and the ongoing marginalisation of patient testimony. The frailty-informed, relational model of care developed in Chapter 6 provides a framework for reform that could be implemented within existing structures.

Adopting a frailty-informed approach would reposition ME/CFS as a chronic, fluctuating condition requiring coordinated and anticipatory care. Like frailty in older adults (Puts and Deeg, 2004), it recognises that vulnerability arises from multisystem depletion rather than from single-organ failure. This framework encourages regular reviews, home-based support, and interdisciplinary coordination across general practice, physiotherapy, occupational therapy, and social care. The outcome would be stability and dignity rather than the cyclical crisis management that currently defines ME/CFS care. A 'frail-proof' model of care.

Professional education must underpin this change. Participants described repeated experiences of disbelief and dismissal, demonstrating a systemic gap in medical understanding. Embedding ME/CFS and related energy-limiting conditions within medical and allied health training would address this deficit. Education should extend beyond biomedicine to include social and ethical dimensions, drawing on feminist care ethics (Tronto, 1993, 2013; Mol, 2008) and disability theory to cultivate compassion, responsiveness and epistemic humility.

At the same time, the thesis exposes an under-recognised opportunity: the vast corpus of patient-generated data already circulating within digital communities. Across forums, social media groups and wikis such as MEpedia, patients collectively record and analyse

symptom patterns, treatment responses and comorbidities with remarkable detail. This material forms part of the *shadow knowledge economy.* A distributed archive of lived evidence that could greatly enhance clinical understanding if ethically integrated into research and policy. Public health agencies and academic institutions should establish partnerships with patient organisations to create voluntary, secure data-sharing frameworks that preserve ownership while enabling synthesis with biomedical datasets. Recognising community-generated data as legitimate evidence would transform both research and clinical practice, bridging the gap between lived and institutional knowledge.

Digital Policy and Inclusion

Digital spaces have become the primary infrastructures of survival for many people with ME/CFS. They provide access to care, community and epistemic participation for individuals often excluded from public life. Yet despite their scale and sophistication, these networks remain largely invisible to policymakers. The thesis demonstrates that forums, wikis and campaign collectives operate as extensions of the welfare and healthcare system—providing not only peer support but structured archives of clinical information, advocacy resources and longitudinal self-tracking data.

Policy must therefore recognise these platforms as integral components of the health and welfare landscape. Initiatives such as MEpedia represent decentralised archives of biomedical and experiential knowledge that rival formal institutional databases in scope and accuracy. Establishing formal partnerships between the NHS, NICE, the National Institute for Health and Care Research (NIHR) and patient-led digital projects could facilitate ethical data sharing and collaborative content verification. In return, institutions could provide infrastructural and accessibility support to ensure the longevity and inclusivity of these platforms.

The shadow knowledge economy generated through digital participation is a valuable national resource, offering insights into patient outcomes, emerging comorbidities and treatment trends that remain invisible in official datasets. Integrating these community-driven datasets into research and service planning would extend public health intelligence while redressing epistemic inequality.

Digital inclusion policy should also address the material barriers to participation. Many people with ME/CFS rely on adaptive technologies such as screen readers, voice-to-text

tools and low-stimulation interfaces. Funding for accessible digital infrastructure and affordable high-speed internet access should be considered essential components of disability rights, not optional extras. Digital accessibility is, in this context, a form of care infrastructure.

Cultural and Public Understanding

Finally, the findings carry significant implications for public discourse and cultural representation. Campaigns such as *Millions Missing* demonstrate how disabled communities use media to transform invisibility into political visibility. Yet broader narratives continue to frame chronic illness as either personal tragedy or moral triumph, depoliticising the structural injustices that underpin disablement.

Public institutions, journalists and educators must collaborate with disabled communities to reframe disability as a matter of justice, not sentimentality. Media representation should shift from depicting suffering as individual weakness to exposing its systemic causes, such as medical neglect, austerity, and bureaucratic disbelief. Cultural policy could support community-led storytelling and archiving projects that preserve and circulate disabled histories as public knowledge.

Such a reframing would contribute to the redistribution of *suffering-capital*, challenging the hierarchies of visibility that determine whose pain is acknowledged and whose is dismissed. By acknowledging that suffering is mediated through cultural, political and technological systems, public institutions can begin to build a more equitable moral economy of recognition. One that treats visibility as a shared social responsibility rather than a privilege.

Future Research Directions

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This thesis has contributed to understanding how people with ME/CFS use digital environments to communicate suffering, build epistemic authority, and navigate systems of care and governance. It has also developed new theoretical tools — *suffering-capital*, the *political–biosocial habitus*, and a *frailty-informed relational model of care* — that reframe how suffering, legitimacy and care circulate across institutional and digital fields. While these findings provide a strong foundation, they also open multiple avenues for further inquiry. Future research could build on this work empirically, theoretically and methodologically, extending its reach across illness contexts, media systems and political structures.

Empirical Extensions

A key priority is comparative research across related chronic and contested conditions. The emergence of Long Covid, for instance, provides an immediate context for testing and expanding the arguments made here. Long Covid shares many features with ME/CFS, such as fluctuating symptoms, diagnostic uncertainty, and the reliance on online networks for validation and support. Comparative analysis could explore how different communities construct digital infrastructures, negotiate medical legitimacy, and convert suffering into epistemic and political capital. Similar comparative studies with fibromyalgia, dysautonomia, or postural orthostatic tachycardia syndrome (POTS) would illuminate how fluctuation, invisibility and disbelief are patterned across illness fields.

Future research could also examine the practical implementation of the frailty-informed model of care proposed in Chapter 6. Policy-focused studies might test its application within NHS pilot schemes or integrated care systems, evaluating outcomes for patients with energy-limiting conditions. This would allow researchers to measure whether coordinated, relational care improves well-being, reduces administrative strain, and strengthens trust between patients and institutions. Such studies could also assess whether the model’s ethical and political commitments, particularly its emphasis on interdependence and fluctuation, can be sustained within the bureaucratic logics of healthcare and welfare governance.

Another promising direction lies in algorithmic ethnography. As digital platforms increasingly shape visibility and public recognition, future research should investigate how

algorithms mediate the representation of chronic illness and disability online. Platform infrastructures determine whose suffering becomes searchable, shareable or monetisable. Examining how automated systems amplify, suppress or commodify illness narratives would extend this thesis's focus on the *moral economies of visibility* into the algorithmic domain. This could involve ethnographic work with platform moderators, content creators and digital activists to trace how illness publics navigate the shifting terrain of algorithmic attention.

Theoretical Avenues

The theoretical contributions developed in this thesis, particularly *suffering-capital* and the *political–biosocial habitus*, invite further development and application. Future work could explore how these concepts function across different biosocial and political fields. For example, *suffering-capital* might be used to analyse how legitimacy and empathy are distributed in climate activism, reproductive health, or mental health movements. Its focus on visibility, affect, and legitimacy makes it a versatile framework for research in media and communication studies as well as sociology and political theory. Understanding how suffering circulates as a form of value within different institutional regimes could deepen analyses of moral and affective governance.

The concept of the *political–biosocial habitus* could be extended to explore collective identity formation within other digitally mediated health movements. Further work might examine how different patient publics consciously cultivate *habitus* through online boundary work, demonstrating that *habitus* is not only an unconscious disposition but also a deliberately produced collective resource. This would build on the argument that digital environments enable new forms of political reflexivity and epistemic agency.

Intersectional analysis offers another critical frontier. The digital communities studied here, while diverse, remain shaped by social stratifications of gender, race, class and digital access. Future research should investigate how these intersecting inequalities mediate participation in digital illness cultures and access to healthcare, welfare and recognition. For example, gendered patterns of credibility, such as long noted in the treatment of ME/CFS and other chronic illnesses, could be examined in conjunction with race and socioeconomic status to reveal how structural privilege shapes who is believed, supported and made visible.

Methodological avenues

Future work could refine the reflexive, care-based approach developed in this study. Extending the model of reflexive care to collaborative, multi-site or comparative digital ethnographies could provide a foundation for researching other populations living with chronic illness or disability. There is also scope to develop mixed-methods designs that integrate patient-generated data from the *shadow knowledge economy* with institutional datasets, creating co-produced evidence bases that bridge lived and biomedical knowledge.

Together, these directions point to a broader research agenda concerned with the politics of recognition, care and legitimacy in an era of digital mediation. Building on this thesis, future studies could continue to challenge where knowledge is located, who is authorised to speak, and how suffering is made meaningful across social, political and technological domains.

Limitations

While this research makes several original contributions to theory, method and practice, it is important to acknowledge its limitations. These do not detract from the study's value but help to situate its findings within a transparent account of scope, design and context.

First, the research was necessarily small in scale, involving fourteen participants alongside extensive netnographic data. This design was chosen to allow depth, reflexivity and sustained engagement, but it inevitably limits the demographic breadth of the sample. The study does not claim representativeness; rather, it prioritises interpretive richness and the capacity to capture the nuanced, fluctuating experiences of people with ME/CFS. However, the findings are transferable, as people with ME/CFS recognise shared scenarios and understandings from their contextualised subjectivities. Further research with larger or more demographically diverse cohorts could extend the empirical reach of these findings and explore how class, race, age and digital access shape participation in illness communities.

Second, the digital and netnographic methods adopted here carry inherent constraints. Online fieldwork privileges those well enough, technologically equipped and socially connected enough to engage in digital life. As a result, the perspectives of those with the most severe forms of ME/CFS, or those who are digitally excluded, may remain under-represented. Although efforts were made to include data from low-energy online environments and asynchronous communication, the research inevitably reflects the voices of those able to participate in digital culture. Future work might combine digital ethnography with home-based or carer-mediated methods to reach those living in extreme isolation.

Third, while the reflexive, insider position of the researcher enabled depth and sensitivity, it also required continuous critical self-awareness. Living with ME/CFS shaped both the form and tempo of the research (pacing interviews, accommodating periods of relapse, and developing adaptive ethical procedures). This positionality was an analytic resource but may also have influenced interpretation in subtle ways. Reflexive journaling and supervisory dialogue were used to mitigate this, yet the findings must be understood as

emerging through the co-constructed and situated perspective of a researcher embedded within the field.

Fourth, the study focused primarily on the UK context. Welfare policy, healthcare systems and disability culture vary considerably across nations. The bureaucratic and affective economies analysed here, particularly those linked to PIP and the Department for Work and Pensions, are culturally and institutionally specific. Comparative research across different welfare regimes would be valuable in testing whether the concepts of suffering-capital and the political–biosocial habitus hold across other policy and cultural contexts.

Fifth, this thesis also recognises the demographic limitations of the participant sample, which was predominantly white, and acknowledges that the study did not adopt a sustained intersectional analytical framework. Consequently, the findings cannot fully account for how race and ethnicity may intersect with chronic illness, disability, gender, and class in shaping experiences of ME/CFS, digital participation, and epistemic legitimacy. Future research would benefit from more explicitly intersectional approaches capable of examining how digital suffering and healthcare marginalisation are experienced across differently racialised and socially positioned groups.

Finally, the thesis reflects the temporal specificity of a rapidly evolving digital landscape. Platforms change, algorithms shift, and online communities migrate. The netnographic data captured a moment in digital culture shaped by particular configurations of Facebook, and the various digital forums, platforms, technologies, wikis, etc, that were syndicated through Facebook forums. Future research should attend to how these dynamics evolve, especially as patient communities increasingly move to decentralised or closed platforms.

Despite these limitations, the methodological choices made here were deliberate and consistent with the study's epistemological stance. The aim was not to generalise statistically but to theorise meaningfully to explore how people with ME/CFS communicate suffering, negotiate legitimacy and construct care within the digital and political infrastructures available to them. In this sense, the constraints of scale, access and embodiment are integral to the phenomena under study. They mirror the very conditions of fatigue, exclusion and adaptation that define life with ME/CFS and the creative social worlds it engenders.

Concluding Reflections

This thesis began with a recognition of absence. The absence of care, of legitimacy, and of representation that has characterised the experience of people with ME/CFS for decades. It set out to examine how those living with this illness use digital spaces to make sense of their suffering, to build networks of knowledge and solidarity, and to confront the structural disbelief that defines their social position. What emerged through this research is a portrait not of passivity, but of resilience and ingenuity. Across online platforms, people with ME/CFS have transformed isolation into connection, and exclusion into a collective practice of meaning-making.

The thesis has contributed to scholarship in several ways. It advances the concept of *suffering-capital* to describe how the labour of communicating illness produces a form of social value: a visibility that can be both empowering and exploitative. It develops the notion of a *political–biosocial habitus*, showing that digital illness communities do not merely reflect existing social structures but consciously generate new ones. It extends the social model of disability by incorporating the fluctuating, embodied dimensions of energy-limiting conditions, and it proposes a *frailty-informed relational model of care* that repositions chronic illness within a framework of interdependence, stability and shared responsibility. These contributions move beyond critique to suggest practical pathways for reimagining care, governance and public understanding.

At the same time, this work demonstrates the methodological possibilities of reflexive and situated research. Conducting this study as a person with ME/CFS shaped every stage of its design, not as a limitation but as an analytic resource. Reflexivity was not a means of self-reference but a mode of care: a way of structuring research that acknowledged fluctuation, exhaustion and trust as integral to knowledge production. This approach enabled a depth of dialogue that might not have been achievable otherwise, particularly with participants for whom energy, attention and memory are scarce resources. It allowed for an ethics of pacing and presence that mirrored the very conditions it sought to understand.

While the research has exposed significant institutional failures, it has also illuminated the transformative potential of digital culture and collective action. The ME/CFS community has built a distributed archive of knowledge — a shadow knowledge economy — that

continues to influence how illness is known, felt and governed. What this study demonstrates is that care and expertise do not only reside in clinics, policies or academic institutions. They are produced in conversation, in shared fatigue, and in the everyday labour of making suffering intelligible. The same digital infrastructures that sustain solidarity also support an evolving practice of collective treatment curation. Within what this thesis identifies as the shadow knowledge economy, patients gather, interpret and test therapeutic information that would otherwise remain inaccessible. These practices represent not only acts of self-care but forms of epistemic resistance, redefining where clinical authority resides and demonstrating that communities historically excluded from biomedical power are capable of generating their own evidence base.

In closing, this thesis argues that understanding chronic illness requires attending to both vulnerability and agency, both exhaustion and creation. It calls for systems that are capable of holding these tensions. Systems that do not pathologise frailty but recognise it as part of the human condition. If this research offers anything to scholarship and to practice, it is the reminder that knowledge is not only generated through certainty, but also through care, patience and relation.

BIBLIOGRAPHY

AbouWarda, H., Qudah, S., Moustafa, A., and He, Y. (2024) ‘How does an online mental health community on Twitter empower diverse population levels?’ *Journal of Medical Internet Research, 26*, e55965. https://doi.org/10.2196/55965

Adair-Toteff, C. (2016) *Max Weber’s sociology of religion*. London: Anthem Press.

Aghaei, S., Nematbakhsh, M.A. and Farsani, H.K. (2012) ‘Evolution of the World Wide Web: from Web 1.0 to Web 4.0’, *International Journal of Web and Semantic Technology*, 3(1), pp. 1–10.

Al-Temimi, A.A., Hassan, Y., Ramli, R., Saad, M.F.M. and Aziz, N.A. (2019) ‘Difficulties facing patients and extra burden for healthcare providers caused by non-adherence to medications: a comprehensive review’, *Indian Journal of Pharmaceutical Education and Research*, 53(4s), pp. S487–S499. https://doi.org/10.5530/ijper.53.4s.143

Alajmi, B. M. (2012). ‘The intention to share: psychological investigation of knowledge sharing behaviour in online communities’. J*ournal of Information and Knowledge Management*, 11(03), 1250022. https://doi.org/10.1142/s0219649212500220

Allan, S. (2022) ‘Care home closure and the influence of domiciliary care supply: evidence from England’, *Journal of European Social Policy*, 32(3), pp. 333–347. https://doi.org/10.1177/09589287221083835

AlMuhaissen, S., AlGhamdi, S., and AlGhamdi, M. (2023). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Epidemiology, pathophysiology, and management. *Journal of Translational Medicine, 21*(1), 1119–1132. https://doi.org/10.1186/s12967-023-04167-4

Alvesson, M. and Sköldberg, K. (2018) *Reflexive methodology: new vistas for qualitative research*. 3rd edn. London: SAGE.

Amolak Bansal (2023) https://me-pedia.org/wiki/Amolak_Bansal [Accessed 14th March 2025] MEpedia

Amputation Foundation (n.d.) ‘Events’. Available at: https://amputationfoundation.org/events/ (Accessed: 18 October 2025).

Anderson, L.A., Morton, L. and Trejo, A.N. (2022) ‘To be young, conscious and black: the cumulative witnessing of racial violence for black youth and families’, *Journal of Family Theory and Review*, 14(3), pp. 412–420. https://doi.org/10.1111/jftr.12466

Anderson, L.A., Morton, L. and Trejo, A.N. (2022) ‘To be young, conscious and black: the cumulative witnessing of racial violence for black youth and families’, *Journal of Family Theory and Review*, 14(3), pp. 412–420. https://doi.org/10.1111/jftr.12466

Archer, M. (2010) ‘Routine, reflexivity, and realism’, *Sociological Theory*, 28(3), pp. 272–303.

Archibald, M., Fraser, K., and Reid, R. (2020). Healthcare provider perspectives on frailty: A barrier to engagement. *Journal of Clinical Nursing*, 29(11–12), 2001–2010.

Bambra, C. and Pope, D. (2007). What are the effects of anti-discriminatory legislation on socioeconomic inequalities in the employment consequences of ill health and disability?. *Journal of Epidemiology and Community Health*, 61(5), 421-426. https://doi.org/10.1136/jech.2006.052662

Bareikytė, M. and Makhortykh, M. (2024) 'Digitally witnessable war from *pereklychka* to propaganda: unfolding Telegram communication during Russia's war in Ukraine', *Media, War and Conflict*, 18(3), pp. 348–365. https://doi.org/10.1177/17506352241255890

Bareket-Bojmel, L., Moran, S. and Shahar, G. (2016) 'Strategic self-presentation on Facebook: personal motives and audience response to online behaviour', *Computers in Human Behavior*, 55, pp. 788–795.

Barnes, C. (1992) *Disabling imagery and the media*. Halifax: Ryburn.

Barnes, C. (2019). *Understanding the Social Model of Disability: Past, Present and Future.* Abingdon: Routledge.

Barnes, E. (2016). *The minority body: A theory of disability.* Oxford: Oxford University Press.

Barnes, M. (2012) *Care in Everyday Life: An Ethic of Care in Practice.* Bristol: Policy Press.

Barua, P., Vicnesh, J., Gururajan, R., Oh, S., Palmer, E., Azizan, M. *et al.* (2022) 'Artificial intelligence enabled personalised assistive tools to enhance education of children with neurodevelopmental disorders: a review', *International Journal of Environmental Research and Public Health*, 19(3), p. 1192. https://doi.org/10.3390/ijerph19031192

Berners-Lee, T., Hendler, J., and Lassila, O. (2001). 'The semantic web'. *Scientific American, 284*(5), 28–37.

Bhandari, A. (2023) 'Anti-systemic movements in the attention economy', *Journal of World-Systems Research*, 29(1), pp. 90–124. https://doi.org/10.5195/jwsr.2023.1100

Bhaskar, R. (1975) *A realist theory of science*. Leeds: Leeds Books.

Bigo, D. (2008) 'Globalized (in)security: The field and the ban-opticon', in Bigo, D. and Tsoukala, A. (eds.) *Terror, Insecurity and Liberty: Illiberal Practices of Liberal Regimes after 9/11*. Abingdon: Routledge, pp. 10–48.

Bimber, B., Flanagin, A. and Stohl, C. (2005) 'Reconceptualizing collective action in the contemporary media environment', *Communication Theory*, 15, pp. 389–413.

Black, C. D., and McCully, K. K. (2005). 'Time course of exercise induced alterations in daily activity in chronic fatigue syndrome'. *Dynamic Medicine, 4*, 10. https://doi.org/10.1186/1476-5918-4-10

Blease, C., Carel, H. and Geraghty, K. (2016) ‘Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome’, *Journal of Medical Ethics*, 43(8), pp. 549–557. https://doi.org/10.1136/medethics-2016-103691

Bogart, K. (2017) ‘Self-identifying as disabled and developing pride in disability aid overall well-being’, *Rehabilitation Psychology* (summary reported in Oregon State University Newsroom, 28 August).

Botha, S. C. B. and Harvey, C. (2024). ‘Doing difference differently: identity (re)constructions of adults with acquired disabilities’. *Rehabilitation Psychology*, 69(3), 280-289. https://doi.org/10.1037/rep0000541

Bourdieu, P. (1984) *Distinction: a social critique of the judgement of taste*. London: Routledge.

Bourdieu, P. (1986). *The forms of capital*. In J. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241–258). Greenwood.

Bourdieu, P. (1992) *Language and symbolic power*. Cambridge: Polity Press.

Bourdieu, P. (2000) *Pascalian meditations*. Cambridge: Polity Press.

Bourdieu, P. (2001) *Masculine domination*. Cambridge: Polity Press.

Bourdieu, P. (2018) *Outline of a theory of practice*, Cambridge: Cambridge University Press

Bourdieu, P. (2020). *Habitus and field, Cambridge:* Polity Press

Bourdieu, P., and Wacquant, L. (1992). *An invitation to reflexive sociology*. University of Chicago Press.
Bowker, G.C. and Star, S.L. (2000) *Sorting things out: classification and its consequences*. Cambridge, MA: MIT Press.

British Journal of Learning Disabilities (2025) ‘Author guidelines’. Wiley Online Library. Available at: https://onlinelibrary.wiley.com/page/journal/14683156/homepage/forauthors.html (Accessed: 20 December 2025).

British Medical Journal (BMJ). (2016). Editorial on PACE trial data reanalysis. *BMJ, 354*, i4964.

Browne, K., Banerjea, N. and Bakshi, L. (2020) ‘Survival and liveability in #COVIDtimes: queer women’s transnational witnessing of COVID-19’, *Dialogues in Human Geography*, 10(2), pp. 128–131. https://doi.org/10.1177/2043820620930833

Bucher, T. (2018) *If…then: algorithmic power and politics*. Oxford: Oxford University Press.

Burgess, A., Miller, V. and Moore, S. (2018) ‘Prestige, Performance and Social Pressure in Viral Challenge Memes: Neknomination, the Ice-Bucket Challenge and SmearForSmear as Imitative Encounters’, *Sociology* (Oxford), V52(5), pp. 1035-1051

Caetano, A. (2014) ‘Personal reflexivity and biography: methodological challenges and strategies’. *International Journal of Social Research Methodology*. V18(2) pp. 227-242

Caiata-Zufferey, M., Abraham, A., Sommerhalder, K., and Schulz, P. J. (2010). ‘Online health information seeking in the context of the medical consultation in Switzerland’. *Qualitative Health Research, 20*(8), 1050–1061. https://doi.org/10.1177/1049732310368404

Callon, M. and Rabeharisoa, V. (2008) ‘The Growing Engagement of Emergent Concerned Groups in Political and Economic Life: Lessons from the French Association of Neuromuscular Disease Patients.’ *Science, Technology and Human Values,* 33(2), pp. 230–261.

Cammaerts, B. (2022) ‘The abnormalisation of social justice: The ‘anti-woke culture war’ discourse in the UK’, *Discourse and Society*, V10(1), pp. 1-14

Campbell, G. (2013) *The hermit in the garden: from Imperial Rome to ornamental gnome*. New Haven, CT: Yale University Press.

Carel, H. (2018). *Phenomenology of illness*. Oxford: Oxford University Press.

Carter-White, R. and Doel, M.A. (2021) ‘The signature of the disaster: witness-ness in death camp and tsunami survivor testimony’, *Transactions of the Institute of British Geographers*, 47(2), pp. 455–469. https://doi.org/10.1111/tran.12511
Cassell, E. J. (2004). *The Nature of Suffering and the Goals of Medicine* (2nd ed.). Oxford University Press.

Castells, M. (2009) *Communication power*. Oxford: Oxford University Press.

Castells, M. (2015) *Networks of outrage and hope: social movements in the internet age*. 2nd edn. Cambridge: Polity Press.

Champagne, P. (1999) The view from the state. In: Pierre Bourdieu et al. *The weight of the world. Social suffering in contemporary society*. USA: Stanford University Press

Chapman, C. M., Louis, W. R., and Masser, B. M. (2018). ‘Identifying (our) donors: toward a social psychological understanding of charity selection in australia’. *Psychology and Marketing*, 35(12), 980-989. https://doi.org/10.1002/mar.21150

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: Sage Publications.

Chen, Y., Li, C., Liang, J., and Tsai, C. (2018). ‘Health information obtained from the Internet and changes in medical decision making: Questionnaire development and cross-sectional survey’. *Journal of Medical Internet Research, 20*(2), e47. https://doi.org/10.2196/jmir.9370

Cheung, C. M., Lee, M., and Lee, Z. W. Y. (2013). ‘Understanding the continuance intention of knowledge sharing in online communities of practice through the post-knowledge-sharing evaluation processes’. *Journal of the American Society for Information Science and Technology*, 64(7), 1357-1374. https://doi.org/10.1002/asi.22854

Chouliaraki, L. (2006) *The Spectatorship of Suffering*, London: Sage Publications

Chouliaraki, L. (2013) *The Ironic Spectator: Solidarity in the age of post-humanitarianism*, Cambridge: Polity Press

Clague-Baker, N. *et al.* (2023a) 'Home-based testing protocol to measure physiological responses to everyday activities in ME: a feasibility study', *Fatigue: Biomedicine, Health andamp; Behavior*, 11(2–4), pp. 142–156. doi: 10.1080/21641846.2023.2245584.

Clague-Baker, N. *et al.* (2023b) 'An International Survey of Experiences and Attitudes Towards Pacing Using a Heart Rate Monitor for People with Myalgic Encephalomyelitis/ chronic Fatigue Syndrome'. *Work*, 74(4) pp. 12225-1234. doi: 10.3233/WOR-220512

Clare, E. (1999) *Exile and pride: Disability, queerness, and liberation*. Cambridge, MA: South End Press.

Clark, D. (2023) Higher education in the UK - Statistics and Facts. *Statista*. [online] Available at: https://www.statista.com/topics/6938/higher-education-in-the-uk/ #topicOverview [Accessed: 8th April 2024]

Coffey, A. (1999) *The ethnographic self: fieldwork and the representation of identity*. London: SAGE.

Cohen, J. and Enserink, M. (2011). 'False positive'. *Science*, 333(6050), 1694-1701. https://doi.org/10.1126/science.333.6050.1694

Collins, R. (2010). *Early Medieval Europe: 300–1000* (3rd ed.). Palgrave Macmillan.

Compston, N., McCallum, F., and Parish, J. (1970). 'Royal Free Hospital outbreak: A reply to McEvedy and Beard'. *British Medical Journal, 1*(1), 7–8.

Conrad, P., and Barker, K. K. (2010). 'The social construction of illness: Key insights and policy implications'. *Journal of Health and Social Behavior, 51*(S), S67–S79.

Corbett, J. B. and Mori, M. (1999) 'Medicine, Media and Celebrities: News coverage of Breast Cancer', 1960-1995, J*ournalism and mass communication quarterly*, V76 (2), Pp. 229-249

Costa C., Burke, C. and Murphy, M. (2018) 'Capturing habitus: theory, method and reflexivity'. *International Journal of Research and Method in Education.* V42(1), pp. 19-32

Costa, C. and Murphy, M. (2015) Bourdieu and the Application of Habitus across the Social Sciences. In: Costa C., Murphy M. (eds) *Bourdieu, Habitus and Social Research*. Palgrave Macmillan, London, pp. 3-17

Costello, J., Patak, L., and Pritchard, J. (2010). 'Communication vulnerable patients in the pediatric ICU: enhancing care through augmentative and alternative communication'. *J Pediatr Rehabil Med,* 3, PP. 289-301

Couldry, N. (2010). *Why Voice Matters: Culture and Politics After Neoliberalism*. SAGE.

Couldry, N. and Hepp, A. (2016) *The mediated construction of reality*. Cambridge: Polity Press.

Couldry, N., and Mejias, U. A. (2019). *The costs of connection: How data is colonizing human life and appropriating it for capitalism*. Stanford University Press.

Crossley, N. (2001) *The Social Body: Habit, Identity and Desire.* London: Sage.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage Publications.

Crow, L. (1992). 'Renewing the social model of disability', IN Barnes, C & Mercer, G (EDS) (1996) Disability & Illness: Exploring the Divide, *Disability Press*

Cueto, I. (2025, March). *ME/CFS research program shuts down at Columbia over Trump cuts* [PDF]. STAT News. https://www.meaction.net/wp-content/uploads/2025/03/FireShot-Capture-040-ME_CFS-research-program-shuts-down-at-Columbia-over-Trump-cuts_-www.statnews.com_.pdf

Dalsgaard, S. (2016) The Ethnographic Use of Facebook in Everyday Life, *Anthropological Forum*, V26(1), pp.96-114

Dan Goodley (2010) 'Learning Difficulties', the Social Model of Disability and Impairment: Challenging epistemologies, *Disability and Society,* 16:2, 207-231, DOI:10.1080/09687590120035816

Daniel, L.C., Lubas, M.M., Wang, H., Szklo-Coxe, M., Ness, K.K., Williams, A.M., Mulrooney, D.A., Howell, R., Leisenring, W., Yasui, Y., Robison, L.L., Armstrong, G.T., Chow, E.J., Krull, K.R. and Brinkman, T.M. (2025), 'Frailty and Sleep in Adult Survivors of Childhood Cancer: A Childhood Cancer Survivor Study Report'. *Psycho-Oncology,* 34: e70098. https://doi.org/10.1002/pon.70098

Davis, H., Assaf, G., McCorkell, L., Wei, H., Low, R., Re'em, Y., … and Akrami, A. (2021). 'Characterizing long covid in an international cohort: 7 months of symptoms and their impact'. *eClinicalMedicine*, 38, 101019. https://doi.org/10.1016/j.eclinm.2021.101019

DecodeME (2023) 'DecodeME Webinar December 2023' [YouTube video], 14 December. Available at: https://www.youtube.com/watch?v=EXjJuQyJxW4 (Accessed: [January 8th 2024]).

DecodeME (n.d.) 'About the ME/CFS Biomedical Partnership'. Available at: https://www.decodeme.org.uk/about-us/ (Accessed: [15th June 2025]).

Degan, T. J., Kelly, P. J., Robinson, L., Deane, F. P., and Smith, A. M. (2020). 'Health literacy of people living with mental illness or substance use disorders: a systematic review'. *Early Intervention in Psychiatry,* 15(6), pp. 1454-1469. https://doi.org/10.1111/eip.13090

Denzin, N.K. and Lincoln, Y.S. (eds) (2011) *The SAGE handbook of qualitative research*. 4th edn. London: SAGE.

Department for Work and Pensions (2025) 'Spring Statement 2025 health and disability benefit reforms – impacts'. GOV.UK, 6 March. Available at: https://www.gov.uk/

government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper/spring-statement-2025-health-and-disability-benefit-reforms-impacts (Accessed: [September 5th 2025]).

Department of Health and Social Care (2023) *My full reality: the interim delivery plan on ME/CFS*. GOV.UK. Available at: https://www.gov.uk/government/consultations/improving-the-experiences-of-people-with-mecfs-interim-delivery-plan/my-full-reality-the-interim-delivery-plan-on-mecfs (Accessed: [October 6th 2025]).

Derrida, J. (1981) 'Plato's Pharmacy', in *Dissemination*. Translated by B. Johnson. Chicago: University of Chicago Press, pp. 61–171.

Deutsche Gesellschaft für ME/CFS (2021) 'Stock photos', 22 November. Available at: https://www.mecfs.de/stockphotos/ (Accessed: June 15th 2025]).

Diaz, M. I., Medford, R. J., Lehmann, C. U., and Petersen, C. (2023). 'The lived experience of people with disabilities during the covid-19 pandemic on twitter: content analysis'. *Digital Health*, 9. https://doi.org/10.1177/20552076231182794

Dolezal, L. and Lyons, B. (2017). 'Health-related shame: an affective determinant of health?'. *Medical Humanities*, 43(4), pp. 257-263. https://doi.org/10.1136/medhum-2017-011186

Dyer, O. (2003). Head of ME association is sacked. *BMJ : British Medical Journal*, *326*(7401), e1232.

Eaton-Fitch, N., Johnston, S. C., Zalewski, P., and Staines, D. R. (2020). 'Health-related quality of life in ME/CFS: A systematic review and meta-analysis'. *Quality of Life Research, 29*(3), pp. 593–605.

Edgerton, R.B. (1967) *Cloak of competence: stigma in the lives of the mentally retarded*. Berkeley, CA: University of California Press.

Elkins, C. (2005). *Imperial Reckoning: The Untold Story of Britain's Gulag in Kenya*. Henry Holt.

Ellis, K. and Goggin, G. (2015) *Disability and the Media: 2 (Key Concerns in Media Studies)*. London: Palgrave Macmillan.

Ellis, K. and Kent, M. (2017) *Disability and Social Media: Global Perspectives*. London and New York: Routledge

Epstein, S. (1996). *Impure Science: AIDS, Activism, and the Politics of Knowledge.* Berkeley: University of California Press.

European Court of Human Rights (2022) 'The European Court grants urgent interim measure in case concerning asylum seeker's imminent removal from the UK to Rwanda' (press release), 14 June. Available at: https://hudoc.echr.coe.int/eng-press#{%22itemid%22:[%22003-7359967-10054452%22]} (Accessed: 21 October 2022).

Eziamaka, N., Odonkor, T., and Akinsulire, A. (2024). 'AI-driven accessibility: transformative software solutions for empowering individuals with disabilities'. *International*

Journal of Applied Research in Social Sciences, 6(8), 1612-1641. https://doi.org/10.51594/ijarss.v6i8.1373

Facebook (2014) The Ice Bucket Challenge on Facebook. *Facebook Newsroom*. [online] Available at: http://newsroom.fb.com/news/2014/08/the-ice-bucket-challenge-on-facebook/. [Accessed: 11th September 2022]

Fadyl, J.K., McPherson, K. and Nicholls, D. (2015) 'Re-creating entrepreneurs of the self: discourses of worker and employee "value" and current vocational rehabilitation practices', *Sociology of Health and Illness*, 37(4), pp. 506–521. https://doi.org/10.1111/1467-9566.12212

Fairclough, N. (1995). *Critical discourse analysis: The critical study of language.* Longman.

Fairclough, N. (2001). Critical discourse analysis as a method in social scientific research. In Wodak R. and Meyer, M. (eds.), *Methods of Critical Discourse Analysi*s (pp. 121-138). London: Sage.

Falaguera-Vera, F., Garcia-Escudero, M., Bonastre-Férez, J., Zacarés, M. and Oltra, E. (2020) 'Pressure point thresholds and ME/CFS comorbidity as indicators of patients' response to manual physiotherapy in fibromyalgia', *International Journal of Environmental Research and Public Health*, 17(21), p. 8044. https://doi.org/10.3390/ijerph17218044

Fanning, R. (2013) *Fatal path: British government and Irish revolution 1910–1922*. London: Faber and Faber.

Fassin, D. (2011) 'A contribution to the critique of moral reason', *Anthropological Theory*, 11(4), pp. 481–491.

Fassin, D. (2020). *The Will to Punish*. Oxford University Press.

Faulkner, J., Ahmed, M., and Patel, T. (2024). 'Frailty in the community pharmacy setting: Exploring professional confidence and barriers to care'. *British Journal of Primary Care*, 33(2), 101–110.

Fawcett, B. and Hanlon, M. (2009). The 'return to community'. *Journal of Sociology,* 45(4), 433-444. https://doi.org/10.1177/1440783309346474

Fazekas, B., Megaw, B., Eade, D. and Kronfeld, N. (2021) 'Insights into the real-life experiences of people living with epilepsy: a qualitative netnographic study', *Epilepsy and Behavior*, 116, p. e107729. https://doi.org/10.1016/j.yebeh.2020.107729

Flick, U. (2018). *An Introduction to Qualitative Research* (6th ed.). SAGE.

Foucault, M. (1977) *Discipline and punish: the birth of the prison*. New York: Pantheon Books.

Foucault, M. (1978). *The history of sexuality, volume 1: An introduction* (R. Hurley, Trans.). Pantheon Books. (Original work published 1976)

Foucault, M. (1980). The confession of the flesh. In C. Gordon (Ed.), *Power/knowledge: Selected interviews and other writings, 1972–1977* (pp. 194–228). Pantheon Books

Fox, J., and Rooney, M. C. (2015). 'The dark triad and trait self-objectification as predictors of men's use and self-presentation behaviors on social networking sites'. *Personality and Individual Differences.* V76, pp. 161–165

Freedom from Torture (2022) 'We did it! Privilege Style pulls out of Rwanda scheme' (blog), 21 October. Available at: https://www.freedomfromtorture.org/news/we-did-it-privilege-style-pulls-out-of-rwanda-scheme (Accessed: 21 October 2022).

Fricker, M. (2007) *Epistemic injustice: power and the ethics of knowing*. Oxford: Oxford University Press.

Fuchs, C. (2014). *Social media: A critical introduction.* London: SAGE.

Fuchs, C. (2015). *Culture and economy in the age of social media.* New York: Routledge.

Fuchs, C. (2020). *Communication and capitalism.* London: University of Westminster Press.

Gan, W., Ye, Z., Wan, S., and Yu, P. S. (2023). *Web 3.0: The future of Internet.* In *Companion Proceedings of the ACM Web Conference 2023* (pp. 123–126). ACM. https://doi.org/10.1145/3543873.3587583

Garland-Thomson, R. (2009) *Staring: How We Look*. Oxford: Oxford University Press.

Gee, J. P. (2014). *An introduction to discourse analysis: Theory and method* (4th ed.). Routledge.

Geraghty, K. (2016). The PACE trial of treatments for chronic fatigue syndrome: A response to White et al. *Journal of Health Psychology, 21*(8), 1183–1190.

Gerrans, P. (2005). "Tacit Knowledge, Rule Following and Pierre Bourdieu's Philosophy of Social Science." *Anthropological Theory.* V5(1), pp. 53–74

Gieryn, T.F. (1983) 'Boundary-work and the demarcation of science from non-science: strains and interests in professional ideologies of scientists', *American Sociological Review*, 48(6), pp. 781–795.

Gillespie, T. (2014) 'The relevance of algorithms', in Gillespie, T., Boczkowski, P.J. and Foot, K.A. (eds) *Media technologies: essays on communication, materiality, and society*. Cambridge, MA: MIT Press, pp. 167–194.

Gilmore, L. (2019) 'Frames of witness: the Kavanaugh hearings, survivor testimony, and #MeToo', *Biography*, 42(3), pp. 610–623. https://doi.org/10.1353/bio.2019.0062

Ginsburg, F. (2012). 'Disability, culture, and the ethnographic record'. In F. Ginsburg and R. Rapp (Eds.), *Disability Worlds* (pp. 107–136). University of California Press.

Glasby, J., Allen, K. and Robinson, S. (2018) 'A game of two halves? Understanding the process and outcomes of English care home closures: qualitative and quantitative perspectives', *Social Policy and Administration*, 53(1), pp. 78–98. https://doi.org/10.1111/spol.12412

Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Anchor Books.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity.* Englewood Cliffs, NJ: Prentice-Hall.

Goggin, G. (2017) 'Internet accessibility and disability policy: lessons for digital inclusion and equality from Australia', *Internet Policy Review*, 6(1). https://doi.org/10.14763/2017.1.452

Goggin, G. (2022). Disability, Internet, and digital inequality: The research agenda. In E. Hargittai (Ed.), *Handbook on Digital Inequality* (pp. 255-273). Edward Elgar.

Goggin, G. and Newell, C. (2003) *Digital Disability; The social construction of disability in New Media.* United Kingdon: Rowman and Littlefield

Goldfarb, B. and Armenta, J. E. (2017) 'Vulnerability in networked space'. In: Ellis, K. and Kent, M. (Eds.) *Disability and Social Media: Global Perspectives*. London and New York: Routledge

Goodley, D. (2010). *Disability studies: An interdisciplinary introduction*. Sage.

Goodley, D. (2014) *Dis/ability Studies: Theorising Disablism and Ableism*. London: Routledge.

Goodley, D., Liddiard, K. and Runswick-Cole, K. (2018) 'Feeling disability: theories of affect and critical disability studies', *Disability and Society*, 33(2), pp. 197–217.

Groenvold, L.V. (2024) *Work and chronic illness in contemporary feminist illness writing 2015–2022*. PhD thesis. Birkbeck, University of London.

Grue, J. (2023) 'The double bind of social legitimacy: on disability, the sick role, and invisible work', *Sociology of Health and Illness*, 46(1), pp. 78–94. https://doi.org/10.1111/1467-9566.13692

Guba, E. G., and Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin and Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Sage Publications.

Guo, A., Kamar, E., Vaughan, J., Wallach, H., and Morris, M. (2020). Toward fairness in AI for people with disabilities: A research roadmap. *ACM SIGACCESS Accessibility and Computing* (125), 1-1. https://doi.org/10.1145/3386296.3386298

Guo, Z., Zhao, S., Guo, N., Wu, Y., Weng, X., Wong, J., Lam, T. and Wang, M. (2021) 'Socioeconomic disparities in eHealth literacy and preventive behaviors during the COVID-19 pandemic in Hong Kong: cross-sectional study', *Journal of Medical Internet Research*, 23(4), p. e24577. https://doi.org/10.2196/24577

Habermas, J. (1989) *The structural transformation of the public sphere: an inquiry into a category of bourgeois society*. Cambridge, MA: MIT Press.

Hadi, F. (2025) ‘UK government’s disability benefit cuts are cruel and unfair’, *BMJ*, 389, p. r811. https://doi.org/10.1136/bmj.r811

Han, B. C. (2018). *Psychopolitics: Neoliberalism and New Power*. Verso.

Handiso, D.W., Paul, E., Boyle, J.A. *et al.* (2024) Course of Depression and Anxiety among Refugees and Asylum Seekers: A Systematic Review and Meta-analysis of Longitudinal Studies. *Int J Ment Health Addiction*. https://doi.org/10.1007/s11469-024-01406-w

Hardt, M. and Negri, A. (2019) Empire, twenty years on. *New left review*. [Online] Available at: doi.org/10.64590/sbk [Accessed: 21st October 2022]

Hassan, M.A., Jamshidi, M.B., Manh, B.D., Chu, N.H., Nguyen, C.-H., Nguyen, Q.H. *et al.* (2023) ‘Enabling technologies for Web 3.0: a comprehensive survey’, *arXiv* preprint. Available at: https://arxiv.org/abs/2401.10901 (Accessed: [June 12th 2025])

Hausmann, E. (2025) ‘Could GPs’ understanding and management of Long Covid and ME be improved by conceptualising those conditions in terms of “premature frailty”?’, *BJGP Life*, 11 April. Available at: https://bjgplife.com/could-gps-understanding-and-management-of-long-covid-and-me-be-improved-by-conceptualising-those-conditions-in-terms-of-premature-frailty/ (Accessed: [November 10th 2025]).

Helberger, N. (2020). ‘The political power of platforms: How current attempts to regulate misinformation amplify opinion power’. *Digital Journalism, 8*(6), 842–854. https://doi.org/10.1080/21670811.2020.1773888

Held, V. (2006) *The Ethics of Care: Personal, Political, and Global*. Oxford: Oxford University Press.

Heyman, R. and Pierson, J. (2015) ‘Social media, delinguistification and colonization of lifeworld’, *Social Media + Society*, 1(2). https://doi.org/10.1177/2056305115621933

Hickman, L. (2023). ‘Willful Dictionaries and Crip Authorship in CART’. In M. Mills and R. Sanchez (Eds.), *Crip Authorship: Disability as Method* (pp. 332–336). NYU Press. http://www.jstor.org/stable/jj.13944206.36

Hidayah, R., Nova, R. and Sari, E.K. (2022) ‘Efforts to enhance mental health among school-aged children during the COVID-19 pandemic through teacher and parent empowerment’, *Journal of Innovation and Applied Technology*, 8(2), pp. 1491–1496. https://doi.org/10.21776/ub.jiat.2022.008.02.10

Hine, C. (2000) *Virtual Ethnography*. London: Sage

Hoijer, B. (2004) ‘The Discourse of Global Compassion: The Audience and Media Reporting of Human Suffering, *Media, culture and society’*, Vol.26 (4), pp. 513-531

Hsu, C., Chiang, Y., and Huang, H. (2012). ‘How experience-driven community identification generates trust and engagement’. Online Information Review, 36(1), 72-88. https://doi.org/10.1108/14684521211206971

Hu, C., Zhao, L., and Huang, J. (2015).'Achieving self-congruency? Examining why individuals reconstruct their virtual identity in communities of interest established within social network platforms'. *Computers in Human Behavior*. V50, pp. 465–475

Hu, X., Bell, R. A., Kravitz, R. L., and Orrange, S. (2012). 'The prepared patient: Information seeking of online support group members before their medical appointments'. *Journal of Health Communication, 17*(8), pp. 960–978. https://doi.org/10.1080/10810730.2011.650828

Huang, S., and Wang, Y. (2023). *'How people with physical disabilities can obtain social support through online videos: A qualitative study in China'. International Journal of Environmental Research and Public Health*, 20(3), e2423. https://doi.org/10.3390/ijerph20032423

Hughes, B. and Paterson, K. (1997) 'The social model of disability and the disappearing body: towards a sociology of impairment', *Disability and Society*, 12(3), pp. 225–240

Hutchinson, J., Checkland, K., Gibson, J., Kontopantelis, E., and Sutton, M. (2023). 'Consequences of the closure of general practices: a retrospective cross-sectional study'. *British Journal of General Practice*, 73(731), e399-e406. https://doi.org/10.3399/bjgp.2022.0501

Ibrahim, Y. (2022) *Technologies of Trauma: Cultural Formations Over Time*, UK: Emerald Publishing

Illich, I. (1976) *Medical nemesis: the expropriation of health*. New York: Pantheon Books.

Illouz, E. (2007) *Cold intimacies: the making of emotional capitalism.* Cambridge: Polity Press.

Institute of Medicine (2015) 'Beyond myalgic encephalomyelitis/chronic fatigue syndrome: redefining an illness'. Washington, DC: National Academies Press.

Ismail, D. K. B., Kane, A., McJury, M., and Kenny, I. (2024). 'Prevalence of health misinformation on social media—challenges and mitigation before, during, and beyond the covid-19 pandemic: scoping literature review'. *Journal of Medical Internet Research*, 26, e38786. https://doi.org/10.2196/38786

Jae-Hyun H., Jin-Seok, L., Oh, H., Eun-Jung, L., Eun-Jin, L., and Chang-Gue, S. (2023). 'Evaluation of viral infection as an etiology of ME/CFS: A systematic review and meta-analysis'. *Journal of Translational Medicine,* V21, pp. 1-10. doi:https://doi.org/10.1186/s12967-023-04635-0

Jagose, A. (1996) *Queer Theory: An Introduction.* New York: New York University Press.

Jenkins, H. (2006) *Convergence culture: where old and new media collide.* New York: New York University Press.

Jenkins, H. (2020) *Spreadable media: creating value and meaning in a networked culture.* New York: New York University Press.

Jenkins, R. (1992). *Pierre Bourdieu*. London: Routledge

Karfakis N. (2018). The biopolitics of CFS/ME. ‘Studies in history and philosophy of biological and biomedical sciences’, 70, pp. 20–28. https://doi.org/10.1016/j.shpsc.2018.05.009

Kaur, M., Kamalyan, L., Abubaker, D., Alheresh, R., and Al-Rousan, T. (2023). ‘Self-reported Disability Among Recently Resettled Refugees in the United States: Results from the National Annual Survey of Refugees’. *Journal of Immigrant and Minority Health, 26*(3), pp. 1-9. DOI:10.1007/s10903-023-01580-4

Kielland, A. and Liu, J. (2025) ‘What can wage development before and after a G93.3 diagnosis tell us about prognoses for myalgic encephalomyelitis?’, *Social Sciences and Humanities Open*, 11, pp. 101206. https://doi.org/10.1016/j.ssaho.2024.101206

Kim, D., Lee, J., and Son, C. (2020).’Systematic review of primary outcome measurements for chronic fatigue syndrome/myalgic encephalomyelitis (cfs/me) in randomized controlled trials. Journal of Clinical Medicine’, 9(11), pp. 3463. https://pmc.ncbi.nlm.nih.gov/articles/PMC7692998/

Kim, H.-W., Zheng, J. R., and Gupta, S. (2011). ‘Examining knowledge contribution from the perspective of an online identity in blogging communities’. *Computers in Human Behavior*. V27, pp. 1760–1770.

Kim, Y., and Baek, Y. M. (2014). ‘When is selective self-presentation effective? An investigation of the moderation effects of “self-esteem” and “social trust”.’ *Cyberpsychology, Behavior, and Social Networking*. V17, pp. 697–701

Kindlon, T. (2017). ‘Do graded exercise therapy and cognitive behavioural therapy harm people with chronic fatigue syndrome?’ *Journal of Health Psychology, 22*(9), pp. 1146–1154.

King, A. (2000) ‘Thinking with Bourdieu Against Bourdieu: A ‘Practical’ Critique of the Habitus’. *Sociological Theory*, V18(3), pp. 417-433

Kingdon, C.C., Bowman, E.W., Curran, H. *et al.* (2018) ‘Functional status and well-being in people with myalgic encephalomyelitis/chronic fatigue syndrome compared with people with multiple sclerosis and healthy controls’, *PharmacoEconomics Open*, 2, pp. 381–392. https://doi.org/10.1007/s41669-018-0071-6

Kinn, A. (2016). ‘Reflections on the social model of distress or madness: how to make the social model of disability accessible to people with mental health challenges’. *Mental Health and Social Inclusion,* 20(4), pp. 231-237. https://doi.org/10.1108/mhsi-06-2016-0018

Kippenberg, H. (2011). *Discovering Religious History in the Modern Age*. Princeton University Press.

Knudsen, A. K., Omenås, A. N., Harvey, S. B., Løvvik, C., Lervik, L. V., and Mykletun, A. (2011). ‘Chronic fatigue syndrome in the media: a content analysis of newspaper articles’. *JRSM Short Reports*, 2(5), 1-6. https://doi.org/10.1258/shorts.2011.011016

Korshakova, E., Marsh, J. K., and Kleinberg, S. (2022). 'Health information sourcing and health knowledge quality: repeated cross-sectional survey'. JMIR Formative Research, 6(9), e39274.

Kozinets, R. (2019). *Netnography: The Essential Guide to Qualitative Social Media Research* (3rd ed.). SAGE.

Kress, G., and van Leeuwen, T. (2020). *Reading images: The grammar of visual design* (3rd ed.). Routledge.

Kuhn, T.S. (1962) *The Structure of Scientific Revolutions*. Chicago: University of Chicago Press.

Lacerda, E. M., Mudie, K., Kingdon, C. C., Butterworth, J. D., O'Boyle, S., and Nacul, L. (2018). 'The UK ME/CFS Biobank: A disease-specific biobank for advancing clinical research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome'. *Frontiers in Neurology, 9*, e1026. https://doi.org/10.3389/fneur.2018.01026

Lapp, C. W. (1997). Exercise limits in chronic fatigue syndrome. *American Journal of Medicine, 102*(1), 21–23.

Lawless, M.T., Archibald, M., Piñero de Plaza, M.A., Drioli-Phillips, P. and Kitson, A. (2020) 'Peer-to-peer health communication in older adults' online communities: protocol for a qualitative netnographic study and co-design approach', *JMIR Research Protocols*, 9(9), p. e19834. https://doi.org/10.2196/19834

Leslie, K. *et al.* (2023) 'An international survey of experiences and attitudes towards transcutaneous auricular vagus nerve stimulation for people with Myalgic Encephalomyelitis/chronic fatigue syndrome', *Fatigue: Biomedicine, Health and Behavior*, 12(1), pp. 32–42. doi: 10.1080/21641846.2023.2286029.

Lim, E.-J., and Son, C.-G. (2018). 'Review of case definitions for ME/CFS'. *Journal of Translational Medicine, 16*(1), e5.

Lincoln, Y. S., and Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.

Lindell, J. (2015) 'Bourdieusian media studies: returning social theory to old and new media'. *Distinktion: Scandinavian Journal of Social Theory.* V16(3), pp.362-377

Lingel, J. (2017) *Digital Countercultures and the Struggle for Community: Digital Technologies and the Struggle for Community*. Cambridge, MA: MIT Press.

Link, B.G. and Phelan, J.C. (2001) 'Conceptualizing stigma', *Annual Review of Sociology*, 27, pp. 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

López-León, S., Wegman-Ostrosky, T., Perelman, C., Sepúlveda, R., Rebolledo, P. A., Cuapio, A., … and Villapol, S. (2021). 'More than 50 long-term effects of covid-19: a systematic review and meta-analysis'. *Scientific Reports*, 11(1). https://doi.org/10.1038/s41598-021-95565-8

Lousley, C. (2014) 'With Love from Band Aid': Sentimental exchange, affective economies, and popular globalism, *Emotion, space and society*, V10, pp. 7-17

MacFarlane, A., Galvin, R., O'Sullivan, M., McInerney, C., Meagher, E., Burke, D., … and LeMaster, J. W. (2016). Participatory methods for research prioritization in primary care: an analysis of the world café approach in Ireland and the USA. Family Practice, cmw104. https://doi.org/10.1093/fampra/cmw104

Machin, D., and Mayr, A. (2012). *How to do critical discourse analysis: A multimodal introduction.* Sage Publications.

Malterud, K., Siersma, V. D., and Guassora, A. D. (2016). 'Sample size in qualitative interview studies: Guided by information power'. *Qualitative Health Research, 26*(13), pp. 1753–1760. https://doi.org/10.1177/1049732315617444

Mankoff, J., Kuksenok, K., Kiesler, S., Rode, J. A., and Waldman, K. (2011). 'Competing online viewpoints and models of chronic illness'. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, 589-598. https://doi.org/10.1145/1978942.1979027

Martin, D. (2022) Britons back Boris Johnson's Rwanda plan, our poll says: Huge support defies hand-wringing critics as survey shows even Labour voters are more for than against scheme to send asylum seekers to Africa. *Daily Mail*. [online] 17th April 2022. Available at: https://www.dailymail.co.uk/news/article-10723057/Britons-Boris-Johnsons-Rwanda-plan-poll-says-Huge-support-defies-hand-wringing-critics.html [Accessed: 21st October 2022]

Martin, N. (2012) 'Disability identity – disability pride, Perspectives': *Policy and Practice in Higher Education*, 16:1, 14-18, DOI: 10.1080/13603108.2011.611832

Mbembe, A. (2019). *Necropolitics*. Duke University Press.

McCall, L. (1992). 'Does gender fit? Bourdieu, feminism, and conceptions of social order'. *Theory and Society, 21*(6), 837–867.

McEvedy, C. P., and Beard, A. W. (1970). 'Royal Free epidemic of 1955: A reconsideration'. *British Medical Journal, 1*(1), 7–11.

McRuer, R. (2006) *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press.

ME Association. (2015). *Patient Survey Report: Graded Exercise Therapy, Cognitive Behavioural Therapy and Pacing*.

Medcalf, A. and Atkin, K. (2024). 'Chronic challenges: picturing chronic disease by the world health organization'. *Medical Humanities*, 51(1), pp. 48-58. https://doi.org/10.1136/medhum-2023-012737

Mencap (2023) *Do You See Me?* London: Royal Mencap Society. Available at: https://www.mencap.org.uk/do-you-see-me (Accessed: [June 5th 2024]).

MEpedia (2023) 'Press release re my Non Compliance Hearing – MPTS – Myhill vs GMC Sept 28 to Oct 1 2020'. Available at: https://www.drmyhill.co.uk/wiki/Press_Release_re_my_Non_Compliance_Hearing_-MPTS-_Myhill_vs_GMC_Sept_28_to_Oct_1_2020 (Accessed: 14 March 2025).

MEpedia. (n.d.). *Amolak Bansal*. https://me-pedia.org/wiki/Amolak_Bansal [Accessed: 6th May 2025]

Michel, M., Sonnenschein, K., and Fischer, S. (2015). 'Quality of life in CFS: A cross-sectional study'. *Journal of Psychosomatic Research, 79*(6), 684–690.

Miguel, E.M., Chou, T., Golik, A., Cornacchio, D, Sanchez, A.L., DeSerisy, M., Comer, J.S. (2017) 'Examining the scope and patterns of deliberate self-injurious cutting content in popular social media', *Depression and anxiety*, V34(9), pp. 786-793

Millar, B. (2022). 'Epistemic obligations and free speech'. *Analytic Philosophy,* 65(2), 203-222. https://doi.org/10.1111/phib.12279

Minnis, G. (2024) 'What is a TENS unit and does it work?', *Medical News Today*. Available at: https://www.medicalnewstoday.com/articles/323632 (Accessed: 1 January 2025).

Mirzoeff, N. (2011) *The right to look: a counterhistory of visuality*. Durham, NC: Duke University Press.

Mol, A. (2008) *The Logic of Care: Health and the Problem of Patient Choice*. London: Routledge.

Monty Python (1967) 'Four Yorkshiremen' [TV sketch], *At Last the 1948 Show*, first broadcast 31 October. [ITV].

Moreland, J., French, T., and Cumming, G. (2015, October 27). 'Exploring online health information seeking in Scotland'. In *The 3rd European Workshop on Practical Aspects of Health Informatics* (Vol. 1574). CEUR-WS. http://ceur-ws.org/Vol-1574/paper8.pdf

Mudie, K., Ramiller, A., Whittaker, S., and Phillips, L. E. (2024). 'Do people with ME/CFS and joint hypermobility represent a disease subgroup? An analysis using registry data'. *Frontiers in neurology*, *15*, e1324879. https://doi.org/10.3389/fneur.2024.1324879

Murray, R., Day, K., and Tobbell, J. (2019). 'Duvet woman versus action man: the gendered aetiology of chronic fatigue syndrome according to english newspapers'. *Feminist Media Studies,* 19(6), 890-905. https://doi.org/10.1080/14680777.2019.1595694

Murthy, D. (2011). 'Twitter: Microphone for the masses?' *Media, Culture and Society, 33*(5), 779–789. https://doi.org/10.1177/0163443711404744

Myhill, S. (2024) https://me-pedia.org/wiki/Sarah_Myhill [Accessed 14th March 2025] MEpedia

Nacul, L., et al. (2011). 'The functional status and well being of people with ME/CFS compared with those with other chronic diseases.' *BMC Public Health, 11*, e402.

Naef, R. (2006). 'Bearing witness: a moral way of engaging in the nurse–person relationship'. *Nursing Philosophy,* 7(3), 146-156. https://doi.org/10.1111/j.1466-769x.2006.00271.x

Napoli, P. M. (2019). *Social media and the public interest: Media regulation in the disinformation age.* Columbia University Press.

Natelson, B.H., Blate, M. and Soto, T. (2022) 'Transcutaneous vagus nerve stimulation in the treatment of long Covid–chronic fatigue syndrome', *medRxiv* preprint. https://doi.org/10.1101/2022.11.08.22281807 (Accessed: 1 January 2025).

National Health Service (2023) *'Chronic fatigue syndrome (CFS/ME): treatment'*. Available at: https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/treatment/ (Accessed: [July 6th 2025]).

National Institute for Health and Care Excellence (NICE). (2021). *Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: Diagnosis and management (NG206)*. NICE.

Nearchou, F., Campbell, A., Duffy, K., Fehily, M., Ryan, H., and Hennessy, E. (2017). 'Chronic illness stigma and well-being in youth: the mediating role of support'. *European Proceedings of Social and Behavioural Sciences*. https://doi.org/10.15405/epsbs.2017.09.1

Neil, S. J. D. and Campbell, E. M. (2020). 'Fake science: xmrv, covid-19, and the toxic legacy of dr. judy mikovits'. *AIDS Research and Human Retroviruses*, 36(7), pp. 545-549. https://doi.org/10.1089/aid.2020.0095

Nixon, N., Simmons, C., Lemieux, J., and Verma, S. (2020). 'Research priorities in metastatic breast cancer: a james lind alliance priority setting partnership'. *The Breast Journal,* 26(3), pp. 488-493. https://doi.org/10.1111/tbj.13525

Noble, S.U. (2018) *Algorithms of oppression: how search engines reinforce racism*. New York: New York University Press.

Oliver, M. (1990) *The politics of disablement*. Basingstoke: Macmillan.

Önen, N.F., Agbebi, A., Shacham, E., Stamm, K.E., Önen, A.R. and Overton, E.T. (2009) 'Frailty among HIV-infected persons in an urban outpatient care setting', *Journal of Infection*, 59(5), pp. 346–352. https://doi.org/10.1016/j.jinf.2009.08.008

Oxtoby, K. (2022) 'Social media a force for good?' *Community Practitioner*, V95(4) pp. 28-31

Palmer, Z., and Oswal, S. (2024). 'Constructing websites with generative AI tools: the accessibility of their workflows and products for users with disabilities.' *Journal of Business and Technical Communication, 39*(1), pp. 93-114. https://doi.org/10.1177/10506519241280644

Papacharissi, Z. (2010) *A private sphere: Democracy in the digital age*. Cambridge, UK: Polity Press

Papacharissi, Z. (2015) *Affective publics: sentiment, technology, and politics.* Oxford: Oxford University Press.

Parker, R. and Aggleton, P. (2003) ‘HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action’, *Social Science and Medicine*, 57(1), pp. 13–24. https://doi.org/10.1016/S0277-9536(02)00304-0

Patel, P. (2022) *UK and Rwanda migration and economic development partnership*, speech 14th April 2022, [online] Available at: https://www.gov.uk/government/speeches/home-secretarys-speech-on-uk-and-rwanda-migration-and-economic-development-partnership [Accessed: 21st October 2022]

Paul, K. (2022) Families sue TikTok after girls died while trying ‘blackout challenge’, *The Guardian*, [online] 6th July, 2022, Available at: https://www.theguardian.com/technology/2022/jul/05/tiktok-girls-dead-blackout-challenge [Accessed: 12th Sept, 2022]

Peng, A.Y., Sun, Y. and Wu, C. (2025) ‘Countering nationalist politics through distant witnessing: an affective-discursive approach’, *Social Media + Society*, 11(2). https://doi.org/10.1177/20563051251337221

Penn, A., Rochester, C., Gosling, G.C., and Zimmeck, M. (2011) *Understanding the Roots of Voluntary Action. Historical Perspectives on Current Social Policy*. Liverpool: University Press

Petersen, A., Schermuly A.C. and Anderson, A. (2019) ‘The shifting politics of patient activism: From bio-sociality to bio-digital citizenship.’ *Health* (London). V23(4) pp. 478-494

Phoenix Rising (2016) ‘The Real ME: a stock photography resource for the media’, 23 March. Available at: https://phoenixrising.me/myalgic-encephalomyelitis-chronic-fatigue-syndrome/the-real-me-a-stock-photography-resource-for-the-media/ (Accessed: [July 24th 2024]).

PhysiosforME (2024) *Now recruiting - vagus nerve stimulation study*. Physiosforme.com. Available at: https://www.physiosforme.com/post/now-recruiting-vagus-nerve-stimulation-study [Accessed: 10th January 2025]

Popper, K. (2002) *The logic of scientific discovery*. London: Routledge Classics.

Prendergast, M. (2018) ‘Witnessing in the echo chamber: from counter-discourses in print media to counter-memories of Argentina’s state terrorism’, *Memory Studies*, 13(6), pp. 1036–1057. https://doi.org/10.1177/1750698018818222

Puts, M.T.E., Lips, P. and Deeg, D.J.H. (2005) ‘Sex differences in the risk of frailty for mortality independent of disability and chronic diseases’, *Journal of the American Geriatrics Society*, 53, pp. 40–47. https://doi.org/10.1111/j.1532-5415.2005.53008.x

Qin, S., Isadore, K., Chun, J., Chen, R. and Mears, M. (2025). ‘Belonging and pride in people with disabilities: An approach to counteract stigma.’ *Stigma and Health,* doi:https://doi.org/10.1037/sah0000619

Renault, E. (2017). *Suffering and Social Inequality*. Springer.

Richardson, A.V. (2020) *Bearing witness while black: African Americans, smartphones, and the new protest #journalism*. Oxford: Oxford University Press.

Richardson, J. (1986). Handbook of theory and research for the sociology of education. Greenwood Press.

Rogers, E. L. (2022). ‘Recursive Debility: Symptoms, Patient Activism, and the Incomplete Medicalization of ME/CFS.’ *Medical Anthropology Quarterly.* V36(3) pp. 412-428

Rogers, E. L. (2023). *Virtual Ethnography. In M. Mills and R. Sanchez (Eds.), Crip Authorship: Disability as Method (pp. 93–98).* NYU Press. http://www.jstor.org/stable/jj.13944206.12

Roland, D. Spurr, J. and Cabrera, D. (2017). Preliminary Evidence for the Emergence of a Health Care Online Community of Practice: Using a Netnographic Framework for Twitter Hashtag Analytics. *J Med Internet Res.* v19(7). Available at: https://www.jmir.org/2017/7/e252/ [Accessed: 27th April 2023]

Rone, J. (2021) ‘“Enemies of the people”? Diverging discourses on sovereignty in media coverage of Brexit’, *British Politics,* V16(1) pp. 1-19

Roy, R., and Malloy, J. (2023). ‘Evolving Role of Social Media in Health Promotion.’ *IntechOpen*. doi: 10.5772/intechopen.111967

Runswick-Cole, K. and Goodley, D. (2013) ‘Resilience: a disability studies and community psychology approach’, *Social and Personality Psychology Compass*, 7(2), pp. 67–78.

Santhouse, A. M., Hotopf, M., and David, A. S. (2010). ‘Chronic fatigue syndrome’. *BMJ*, 340(feb11 1), c738-c738. https://doi.org/10.1136/bmj.c738

Sarah Myhill (2024) https://me-pedia.org/wiki/Sarah_Myhill [Accessed 14th March 2025] MEpedia

Saussure, F. de (1959) *Course in general linguistics*. New York: Philosophical Library.

Schatzki, T. (1987). “Overdue Analysis of Bourdieu’s Theory of Practice.” *Inquiry*. V30(1–2), pp. 113–135.

Scheibenbogen, C., Freitag, H., Blanco, J., Capelli, E., Lacerda, E., Authier, J., … and Murovska, M. (2017). T’he european me/cfs biomarker landscape project: an initiative of the european network euromene’. *Journal of Translational Medicine,* 15(1). https://doi.org/10.1186/s12967-017-1263-z

Scott-Samuel, A., Bambra, C., Collins, C., Hunter, D. J., McCartney, G., and Smith, K. E. (2014). ‘The impact of thatcherism on health and well-being in britain.’ *International Journal of Health Services,* 44(1), pp. 53-71. https://doi.org/10.2190/hs.44.1.d

Sevenhuijsen, S. (2003) ‘The place of care: the relevance of the feminist ethic of care for social policy’, *Feminist Theory*, 4(2), pp. 179–197.

Shakespeare, T. (2014) *Disability rights and wrongs revisited*. London: Routledge.

Shakespeare, T. and Watson, N. (1997) Defending the social model, *Disability and Society*, 12(2), pp. 293–300

Shakespeare, T., Watson, N. and Alghaib, O.A. (2016) ‘Blaming the victim, all over again: Waddell and Aylward’s biopsychosocial (BPS) model of disability’, *Critical Social Policy*, 37(1), pp. 22–41. https://doi.org/10.1177/0261018316649120

Shepherd, C. (2023) https://me-pedia.org/wiki/Charles_Shepherd#Media_coverage_about_Dr_Shepherd [Accessed 14th March 2025] MEpedia

Shepherd, C. (2021). Charities, patients, and researchers are working together to find the cause and effective treatments for me/cfs. *BMJ*, n1854. https://doi.org/10.1136/bmj.n1854

Shepherd, C. (2022). ME Association ME/CFS/PVFS Clinical and Research Guide 2022 Edition (The 'Purple Book’). UK: The ME Association.

Shildrick, M. (2009). *Dangerous Discourses of Disability, Subjectivity and Sexuality*. Basingstoke: Palgrave Macmillan.

Shultz, L. and Karsgaard, C. (2023) ‘Taming global citizenship education within Twitter’s attention economy’, *Journal of Creative Communications*, 19(1), pp. 13–31. https://doi.org/10.1177/09732586231198960

Shuo Wang et al. (2023) ‘Frailty and pre-frailty associated with physical functional performance and quality of life in breast cancer and bone marrow transplant survivors’. *JCO* 41, 12064-12064. DOI:10.1200/JCO.2023.41.16_suppl.12064

Silva, C.F. and Howe, P.D. (2012) ‘The (in)validity of supercrip representation of Paralympian athletes’, *Journal of Sport and Social Issues*, 36(2), pp. 174–194.

Simon, H.A. (1971) ‘Designing organizations for an information-rich world’, in Greenberger, M. (ed.) *Computers, communication, and the public interest.* Baltimore, MD: Johns Hopkins University Press, pp. 37–72.

Soffer, M. and Ajzenstadt, M. (2010). ‘Stigma and otherness in the israeli media’s mirror representations of illness.’ *Qualitative Health Research*, 20(8), pp. 1033-1049. https://doi.org/10.1177/1049732310369803

Staley, K., Crowe, S., Crocker, J., Madden, M., and Greenhalgh, T. (2020). ‘What happens after james lind alliance priority setting partnerships? a qualitative study of contexts, processes and impacts.’ *Research Involvement and Engagement*, 6(1). https://doi.org/10.1186/s40900-020-00210-9

Stetten, N. E., LeBeau, K., Aguirre, M. A., Vogt, A. B., Quintana, J. R., Jennings, A. R., and Hart, M. (2019). ‘Analizing the communication interchange of individuals with disabilities utilising Facebook, Discussion Forums, and chat rooms: Qualitative content analysis of online disabilities support groups.’ *JMIR rehabilitation and assistive technologies.* Vol.6 (2), p.e12667-e12667

Stevens S.R. and Davenport T.E. (2010) ‘Functional outcomes of anaerobic rehabilitation in a patient with chronic fatigue syndrome: case report with 1-year follow-up.’ *Bulletin of the IACFS/ME*. v18(3): pp. 93–98

Stewart, M. (2019). ‘Preventable harm: creating a mental health crisis.’ *Journal of Public Mental Health*, 18(4), pp. 224-230. https://doi.org/10.1108/jpmh-07-2019-0070

Stiegler, B. (2011) Distrust and the Pharmacology of Transformational Technologies. *In. Quantum Engagements.* Zülsdorf T. B. et al. (Eds.). US: IOS Press

Stiegler, B. (2013) *What makes life worth living: On Pharmacology.* Cambridge: Polity Press

Strain, W. D., Sherwood, O., Banerjee, A., Togt, V. v. d., Hishmeh, L., and Rossman, J. S. (2022). ‘The impact of covid vaccination on symptoms of long covid: an international survey of people with lived experience of long covid.’ *Vaccines*, 10(5), e652. https://doi.org/10.3390/vaccines10050652

Sugiura, L. (2021) *The Incel Rebellion : The Rise of the Manosphere and the Virtual War Against Women*. Bingley : Emerald Publishing Limited

Sumiala, J. (2019) ‘Agony at a distance: investigating digital witnessing on YouTube’, in Hepp, A. and Hasebrink, U. (eds) *Ethik in mediatisierten Welten*. Wiesbaden: Springer VS, pp. 131–145. https://doi.org/10.1007/978-3-658-26212-9_8

Suratwala, T. (2024) ‘Feelings of “stigma, shame, and guilt”: an inductive thematic analysis exploring the lived experiences of eating disorders’ [preprint]. https://doi.org/10.21203/rs.3.rs-3944022/v1 (Accessed: [March 15th 2025]).

Svensson, J., Fjellfeldt, M., and Johansson, S. (2024). ‘Controlling Internet use: A contemporary way of excluding people with intellectual disabilities? Mapping and understanding Internet use in Sweden from a critical perspective.’ *Scandinavian Journal of Disability Research, 26*(1), pp. 505-524. https://doi.org/10.16993/sjdr.1132

Swain, J., and French, S. (2000). ‘Towards an Affirmation Model of Disability.’ *Disability and Society*, *15*(4), pp. 569–582. https://doi.org/10.1080/09687590050058189

Tenderich, A., Tenderich, B., Barton, T., and Richards, S. E. (2019) ‘What Are PWDs (People With Diabetes) Doing Online? A Netnographic Analysis,’ *Journal of Diabetes Science and Technology*, Vol. 13(2) pp. 187–197

Tharoor, S. (2018) *Inglorious empire: what the British did to India*. London: Penguin.

The ME Association (2018) ‘The ME Association “Real M.E.” photo campaign’, 5 February. Available at: https://meassociation.org.uk/2018/02/the-me-association-real-m-e-photo-campaign-05-february-2018/ (Accessed: [July 30th 2025]).

The ME Association (2025) ‘Update: UK ME/CFS Biobank Steering Group’, 7 April. Available at: https://meassociation.org.uk/2025/04/update-uk-me-cfs-biobank-steering-group/ (Accessed: July 25th 2025]).

The ME Association. (2025, April 7). *Update: UK ME/CFS Biobank Steering Group*. https://meassociation.org.uk/2025/04/update-uk-me-cfs-biobank-steering-group/

Titscher, S., Meyer, M., Wodak, R., and Vetter, E. (2000). *Methods of text and discourse analysis*. Sage Publications.

Tofani, M. (2022). ‘Measuring disability among migrants with Washington Group tools: Evidence from refugees and asylum seekers’. *International Journal of Environmental Research and Public Health, 19*(24), e16520. 10.3390/healthcare10101860

Tomkow, L. (2018) ‘The biopolitics of frailty: a critical discourse analysis’, *Social Science and Medicine*, 211, pp. 699–707.

Tronto, J. C. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.

Tronto, J. C. (2013) *Caring Democracy: Markets, Equality and Justice.* New York: NYU Press.

Tschopp, R., König, R. S., Rejmer, P., and Paris, D. H. (2023). Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): A preliminary survey among patients in Switzerland. *Heliyon*, *9*(5), e15595. https://doi.org/10.1016/j.heliyon.2023.e15595

Udoudom, U., Bassey, B. E., George, K., and Etifit, S. (2024). ‘Impact of symbolic interactionism, pragmatism and social constructionism on communication and media practice.’ *International Journal of Humanities, Education, and Social Sciences,* 2(1), pp. 1-25. https://doi.org/10.58578/ijhess.v2i1.2547

Underhill, R., and Baillod, J. (2021). Revisiting the Royal Free Hospital outbreak. *Journal of Translational Medicine, 19*(1), 8.

Vainauskienė, V. and Žemaitaitienė, G. (2023). ‘The dynamics of knowledge sharing in chronically ill patient-led online health communities.’ *The International Journal of Health Planning and Management,* 39(2), 397-416. https://doi.org/10.1002/hpm.3733

van Alem, J. L. L., Frielink, N., and Embregts, P. J. C. M. (2025). ‘Social internet use by people with intellectual disabilities: A systematic review and thematic synthesis of qualitative studies.’ *Journal of Intellectual Disability Research, 69*(4), pp. 243-264. https://doi.org/10.1111/jir.13211

van Campen, C. , Rowe, P. and Visser, F. (2020) ‘Validity of 2-Day Cardiopulmonary Exercise Testing in Male Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.’ *Advances in Physical Education*, v10, pp. 68-80. doi: 10.4236/ape.2020.101007.

van Dijck, J. (2013) *The culture of connectivity: A critical history of social media*. Cambridge, UK: Polity Press

van Dijck, J., Poell, T., and de Waal, M. (2018). *The platform society: Public values in a connective world.* Oxford University Press.

van Dijk, A. T. (1997). *Discourse as structure and process of discourse studies: A multidisciplinary introduction. Volume I.* SAGE Publications, London.

van Dijk, A. T. (2001). Multidisciplinary Critical Discourse Analysis: A plea for diversity. In Wodak, R. and Meyer, M. (eds.), *Methods of Critical Discourse Analysis* (pp. 95-120). London: Sage.

Van Oosterwijck, J., et al. (2010). ‘The role of exercise in ME/CFS’. *Journal of Internal Medicine, 268*(3), pp. 265–278.

Varesi, A., Deumer, U. S., Ananth, S., and Ricevuti, G. (2021). ‘The Emerging Role of Gut Microbiota in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Current Evidence and Potential Therapeutic Applications.’ *Journal of clinical medicine*, *10*(21), e5077. https://doi.org/10.3390/jcm10215077

Vicari, S. and Cappai, F. (2016) ‘Health activism and the logic of connective action. A case study of rare disease patient organisations,’ *Information, Communication and Society*, V19(11), pp. 1653-1671

Vink, M., and Vink-Niese, F. (2019). ‘Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies.’ *Diagnostics (Basel, Switzerland)*, *9*(4), 124. https://doi.org/10.3390/diagnostics9040124

Violet, T.K. (2022) *‘It’s hell’: examining suspicion, ableism, and disability pride through an intersectional analysis of fibromyalgia experiences*. Doctoral dissertation. [Institution]. Available at: https://www.proquest.com/dissertations-theses/hell-examining-suspicion-ableism-disability-pride/docview/2713457958/se-2 (Accessed: [12th May 2025]).

Visible (2024a) ‘Pacing made simple’. Available at: https://www.makevisible.com/ (Accessed: 11 November 2024).

Visible (2024b) ‘About’. Available at: https://www.makevisible.com/about (Accessed: 11 November 2024).

Vyas, J., Muirhead, N., Singh, R., Ephgrave, R., and Finlay, A. (2022). ‘Impact of myalgic encephalomyelitis/chronic fatigue syndrome (me/cfs) on the quality of life of people with me/cfs and their partners and family members: an online cross-sectional survey’. *BMJ* Open, 12(5), e058128. https://doi.org/10.1136/bmjopen-2021-05812

Wacquant, L. (2013a) ‘Habitus as Topic and Tool: Reflections on Becoming a Prizefighter’, in D. Spencer and R. Sánchez García (eds.) *Fighting Scholars: Habitus and Ethnographies of Martial Arts and Combat Sports*. Anthem Press (Key Issues in Modern Sociology), pp. 19–32.

Wacquant, L. (2013b) ‘Homines in extremis: What fighting scholars teach us about Habitus’, *Body and Society*, V20(2), pp. 3-17

Wald, M. (2021). ‘AI data-driven personalisation and disability inclusion.’ *Frontiers in Artificial Intelligence, 3*. https://doi.org/10.3389/frai.2020.571955

Wallace, R., Costello, L. and Devine, A. (2018) ‘Netnographic Slog: Creative Elicitation Strategies to Encourage Participation in an Online Community of Practice for Early Education and Care.’ *International Journal of Qualitative Methods*. V17, pp. 1-13

Walston, J., Hadley, E.C., Ferrucci, L., Guralnik, J.M., Newman, A.B., Studenski, S.A., Ershler, W.B., Harris, T. and Fried, L.P. (2006) ‘Research agenda for frailty in older adults:

toward a better understanding of physiology and aetiology', *Journal of the American Geriatrics Society*, 54, pp. 991–1001. https://doi.org/10.1111/j.1532-5415.2006.00745.x

Warmoth, K., Lang, I. A., Phoenix, C., Abraham, C., and Tarrant, M. (2015). 'Thinking you're old and frail': A qualitative study of frailty in older adults. *Ageing and Society*, 36(7), pp. 1483–1500.

Waters, A., et al. (2020). 'Reanalysis of the Royal Free outbreak: Evidence for infectious origin.' *Medical Hypotheses, 142*, e109739.

Weber, M. (1993). *The Sociology of Religion*. Beacon Press.

Weiss, G. (1999). *Body images: Embodiment as intercorporeality.* London: Routledge.

Wendell, S. (1997) Towards a feminist theory of disability, in: J.L. DAVIS (Ed.) *The Disability Studies Reader.* London: Routledge.

Wexler, M. G. and Dole, C. (2022). 'Giving care a platform: the use of instagram by mothers of children with chronic illness.' Medicine Anthropology Theory, 9(3), pp. 1-20. https://doi.org/10.17157/mat.9.3.5768

White, P., Goldsmith, K., Johnson, A., and Chalder, T. (2011). 'Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): A randomised trial.' *The Lancet, 377*(9768), pp. 823–836.

Wilkinson, I. (2005). *Suffering: A Sociological Introduction*. Polity Press.

Wilkinson, I., and Kleinman, A. (2016). *A passion for society: How we think about human suffering. University of California Press.*

Wirth, K. J., and Löhn, M. (2023). 'Myalgic Encephalomyelitis/Chronic fatigue syndrome (ME/CFS) and comorbidities: Linked by vascular pathomechanisms and vasoactive mediators?' *Medicina, 59*(5), e978. doi:https://doi.org/10.3390/medicina59050978

Wodak, R. (2001). What Critical Discourse Analysis is about-a summary of its history, important concepts and its developments. In R. Wodak and M. Meyer (eds.), Methods of Critical Discourse Analysis (pp. 1-13). London: Sage.

Wodak, R. (2009). Critical discourse analysis: history, agenda, theory, and methodology. In R. Wodak and Meyer (eds), *Methods of Critical Discourse Analysis* (pp. 1-33) 2nd edition London: Sage.

Wolbring, G. (2024) 'From supercrip to techno-supercrip', *Current Issues in Sport Science*, 9(1), Article 004. https://doi.org/10.36950/2023.3ciss007

Wolbring, G., and Ghai, A. (2024). '*A*cademic coverage of online activism of disabled people: A scoping review'. *Societies, 14*(11), e215. https://doi.org/10.3390/soc14110215

Wolfensberger, Wolf P.; Nirje, Bengt; Olshansky, Simon; Perske, Robert; and Roos, Philip, "The Principle of Normalization In Human Services" (1972). Books: Wolfensberger Collection. 1. https://digitalcommons.unmc.edu/wolf_books/1

Wong, D. K., and Cheung, M. (2019). Online health information seeking and eHealth literacy among patients attending a primary care clinic in Hong Kong: A cross-sectional survey. *Journal of Medical Internet Research, 21*(3), e10831. https://doi.org/10.2196/10831

Wu, X. and Montgomery, M. (2019) 'Witnessing in crisis contexts in the social media age: the case of the 2015 Tianjin blasts on Weibo', *Media, Culture and Society*, 42(5), pp. 675–691. https://doi.org/10.1177/0163443719855300

Xian, L., Vickers, S.D., Giordano, A.L., Lee, J., Kim, I.K., and Ramaswamy, L. (2019) Selfharm on Instagram: Quantitative Analysis and Classification of Non-Suicidal Self-Injury. *2019 IEEE First International Conference on Cognitive Machine Intelligence* (*CogMI*) [online] Available at: https://ieeexplore.ieee.org/document/8998990 [Accessed: 12th Sept, 2022]

Xu, J., Kent, M., Ellis, K. and Zhang, H. (2017) Using social media to advance the social rights of people with disability in China. In: Ellis, K. and Kent, M. (Eds.) *Disability and Social Media: Global Perspectives*. London and New York: Routledge

Xue, K., Wang, Y., Wang, X., Chen, P., Xiao, C., Fu, J., … and Cui, J. (2021). 'The efficacy and safety of moxibustion for chronic fatigue syndrome.' *Medicine*, 100(18), e25742. https://doi.org/10.1097/md.0000000000025742

Yang, F., Yue, B., Ma, H., and Yuan, Y. (2022). 'Acupuncture and moxibustion for chronic fatigue syndrome: a systematic review and network meta-analysis.' *Medicine*, 101(31), e29310. https://doi.org/10.1097/md.0000000000029310

Yeo, J. Y., Lim, C. J., Yang, S., and Tan, B. Y. (2024). 'How does shame relate to clinical and psychosocial outcomes in knee osteoarthritis?.' *Clinical Orthopaedics and Related Research,* 483(4), pp. 558-570. https://doi.org/10.1097/corr.0000000000003329

Ylä-Anttila, T. (2020) 'Social media and the emergence, establishment and transformation of the right-wing populist Finns Party', *Populism*, 3(1), pp. 121–139. https://doi.org/10.1163/25888072-02021043

Young, S. (2014) 'I'm not your inspiration, thank you very much' [video], TEDxSydney. Available at: [https://www.youtube.com/watch?v=8K9Gg164BswL] (Accessed: [September 12th 2025]).

Zdravkova, K., Krasniqi, V., Dalipi, F., and Ferati, M. (2022). 'Cutting-edge communication and learning assistive technologies for disabled children: an artificial intelligence perspective'. *Frontiers in Artificial Intelligence, 5*. https://doi.org/10.3389/frai.2022.970430

Zhang, Y., Wells, C., Wang, S. and Rohe, K. (2017) 'Attention and amplification in the hybrid media system: the composition and activity of Donald Trump's Twitter following during the 2016 presidential election', *New Media and Society*, 20(9), pp. 3161–3182. https://doi.org/10.1177/1461444817744390

Žižek, S. (2014) *Trouble in paradise: from the end of history to the end of capitalism*. London: Allen Lane.

Zuboff, S. (2019) *The age of surveillance capitalism: the fight for a human future at the new frontier of power*. London: Profile Books.

Appendix: Participant Journal Template

LIVERPOOL JOHN MOORES UNIVERSITY

PARTICIPANT TEXT-BASED JOURNAL:

Dear participant, thank you for expressing interest in this research project. This research is being conducted through the School of Humanities and Social Science at Liverpool John Moores University. It aims to understand how people with ME/CFS use technology to both find support and information about ME/CFS. Ethical approval number: 22/HSS/008.

Please return completed journals to: [researcher's email address]

You have three months to complete this journal. There are 4 sections to complete. When answering the questions in this journal, please don't complete the form in one go. It is designed for you to return to it and add to it over the coming months. Some of your answers may be very short, some may be longer; all lengths of response are interesting, so don't feel pressured to write more than you feel you want to. Don't worry about sentence structure, spelling or grammar. If, for any reason, there are questions you don't want to answer, just leave them blank.

PLEASE INDICATE YOUR AGE BRACKET WITH AN X

<18 years	18-29	30-45	46-60	60-70	>70

PLEASE INDICATE YOUR GENDER

GENDER

PLEASE INDICATE YOUR HIGHEST LEVEL OF EDUCATION WITH AN X

HIGH SCHOOL	FURTHER EDUCATION	UNDERGRADUATE DEGREE	MASTERS DEGREE	PHD/ DOCTORATE	OTHER

The following journal consists of four sections:

Section A does not require you to keep coming back to it over time, whereas sections B, C and D can be added to as you think of things, or as you engage with online media over time. This journal is not to be thought of as a linear diary, rather, as a place to add your thoughts, reflections, and experiences over time.

A, B, C, and D. Primary questions are in blue, with follow-up questions below them in black.

SECTION A: YOUR RELATIONSHIP WITH ME/CFS

1. Have you received a diagnosis of ME/CFS from a medical practitioner?

Yes	No

Time before official diagnosis	Time since official diagnosis

2. ME/CFS is often categorised by severity. How would you categorise the severity of your illness?

MILD	MODERATE	SEVERE	VERY SEVERE	DON'T KNOW

3. Would you describe your illness as:

STABLE	RELAPSING AND REMITTING	DECLINING	IMPROVING	FLUCTUATING	OTHER

4. What was the process of gaining a diagnosis like for you?

***ANSWER*:**

- Was the process lengthy?
- Who gave you the diagnosis, e.g., GP, Psychiatrist, ME/CFS clinic, or other?
- How did the process make you feel? Were you listened to?

5. I've been referring to this illness as ME/CFS. What do you think about that name?

***ANSWER*:**

- Have you heard of any of the other names either used officially or as slang to describe it?
- What do you think about these other names?
- Do you think the name has an impact on how people with ME/CFS are perceived? Why do you think this is important or not important?
- What name do you use to describe the illness?

6. Who or where do you get your support from to manage your illness?
***ANSWER*:**

- Has your GP been helpful? Are you getting the support you need?
- Do you attend any ME/CFS clinics or pain clinics? Have they been informative/helpful?
- Have you implemented or tried any therapies or treatments that you discovered independently from your ME/CFS healthcare providers?

7. PEM (Post Exertional Malaise) is described as a worsening of symptoms. How would you describe what happens to you? Do you experience any symptoms that are distinct to PEM?

***ANSWER*:**

B: ME/CFS REPRESENTATIONS IN SOCIETY

1. What do you think people without ME/CFS think ME/CFS is?

***ANSWER*:**

- What do you think is the biggest misconception about the illness?

2. What symptoms of ME/CFS do you think cause the most suffering?

***ANSWER*:**

- Do you think friends and family or wider society understand your reality of living with ME/CFS?

3. How do the opinions of family and friends affect how you feel about ME/CFS?

***ANSWER*:**

C: THE REPORTING OF ME/CFS IN LEGACY MEDIA (PRINT, RADIO, TV)

1. **How do you feel ME/CFS has been reported in the media over the years? Can you think of examples? Can you think of recent examples?**

***ANSWER*:**

2. Do you think legacy media such as TV, Radio and Newspapers report well on ME/CFS?

***ANSWER*:**

- Are you aware of the 'Pace trial'?
- Do you have any thoughts on how this was reported?
- Are you aware of the new NICE guidelines regarding ME/CFS? What do you think about these changes?
- Do you think they will have any repercussions, either positive or negative?

3. Have you noticed any difference on the reporting of ME/CFS since we have been experiencing what is currently being referred to as 'Long-COVID'?

***ANSWER*:**

- Do you see similarities or perhaps differences in the way Long-COVID is being reported on compared to how ME/CFS is spoken about in the media?
- Do you think Long-COVID reporting will help people with ME/CFS? If so, how?

D: USING THE INTERNET AND/OR TECHNOLOGY TO SUPPORT INFORMATION SHARING AND SOURCING ABOUT ME/CFS?

1. On an average day, how much time do you spend using the internet or digital communication technologies?

Less than 1 hour	1-2 hours	3-4 hours	More than 4 hours

2. Do you use any other communication technologies? Which ones (please specify)?

3. Are you a member of or do you follow any social media groups or forums that offer information or support to people with ME?CFS?

Yes	No

4. Are there places that you go online to gather news or information about ME/CFS research? This could be, for example, the websites of charitable organisations, government information sites, healthcare sites or community-led forums.
ANSWER:

5. Are there places you go online to connect with ME/CFS communities? Can you share some experiences of these?
***ANSWER*:**

6. Are there places you go online to find out information or to gain support such as help accessing state benefits or help with care? Can you share some experiences of this?
***ANSWER*:**

7. Do you ever use social media or digital forums to talk about your experiences of living with ME/CFS? Can you share some examples of this?
***ANSWER*:**

8. Does the information that you gather through your own research about ME/CFS always match the information you get from health professionals? Can you share some details about this?
***ANSWER*:**

9. Have you used any of the information you have gathered from your own research to influence any of your treatment protocols? Can you share some details or examples of this?
***ANSWER*:**

10. Has any engagement in online activity (such as ME/CFS forums, social media pages, information sites) helped you manage your health and wellbeing? Can you share some examples of this?
***ANSWER*:**

11. Have you published any literature, such as a blog, an article, or a book, about your experiences with ME/CFS or about your research or findings about ME/CFS? If so, please tell me a little about this process. Are you currently engaging in such activities?
***ANSWER*:**

12. Is there anything you would like to add that you think may be relevant?
***ANSWER*:**

Thank you for completing the journal and taking part in this research.

You can continue to return to this journal over the next three months and add thoughts, memories, or real-time instances as they occur.