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The Embodied Liminality of Fibromyalgia:  
Chronic Illness Norms and Conceptions

By

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## **Abstract**

This study explores the associated life experiences of being diagnosed with fibromyalgia affects how individuals conceptualize life narratives and their relations to their cultural backgrounds, thereby transforming their sense of self. Fibromyalgia is characterized by symptoms such as fatigue and widespread musculoskeletal pain (“Fibromyalgia | Arthritis | CDC” n.d.). The symptoms experienced are inconsistent across patients but other listed common symptoms may include sleep disorders, brain fog, IBS and mental health concerns, etc. (“Fibromyalgia | Arthritis | CDC” n.d.). Diagnosing a disease such as fibromyalgia is a difficult task for both doctors and patients. The difficulty arises out of the fact that the patient experiences intense symptoms but there are often no clinical signs to determine as evidence of illness. As a result, no diagnosis is ever concluded or an eventual diagnosis is made through exclusionary factors rather than through the evidence of clinical signs. All the while the patient is likely experiencing prolonged unexplainable and unending symptoms, that has no clear origin or end. Through interviewing fibromyalgia patients, this study explores the associated dissolution of one’s conception of self throughout the illness experience as a result of transformed social and embodied norms. This research process was examined and analyzed through George Canguilhem’s work on normativity and the anthropological understanding of liminality and embodiment.

## Introduction

The experience of long-term chronic illness is complex and difficult to convey. Chronic illness patients often meet obstacles in finding treatment and proper diagnosis. Fibromyalgia is one such illness that deserves earnest study. The long name roughly translates to fibrous connective tissue pain and affects anywhere between 2-4% of the United States population, more commonly diagnosed in women (Galvez-Sánchez and Reyes del Paso 2020). Diagnosing a disease such as fibromyalgia is a difficult task for both doctors and patients. Furthermore, there is debate among many medical professionals on whether or not fibromyalgia exists (Häuser and Fitzcharles 2018). Clinicians from various backgrounds have weighed in on the issue. The difficulty arises out of the fact that the patient experiences intense symptoms but there are often no clinical signs to determine as evidence of illness. As a result, no diagnosis is ever concluded or a diagnosis is made through exclusion rather than through evidenced clinical signs. All the while the patient is likely experiencing a prolonged unexplainable and unending pain, that has no clear origin or end.

The mystery surrounding fibromyalgia leads me to ask a certain question: How do the associated life experiences of fibromyalgia affect an individual's life narrative and relation to their cultural background, thereby transforming their sense of self? I hypothesize that there is a dissolution of a former conception of self during the duration of illness as a result of transformed norms. Meaning that symptomatic distress, whether somatic or psychogenic, cannot fully explain the pathology of a shift in one's lived experience. Individuals build comprehension of their subjective experiences through narrative and meaning-making. The implied subjective experience of illness and associated symptoms, then, provides an object of study that is difficult to convey and therefore has implications in how affected individuals create norms within

changed and continually changing lives as per constraints such as illness and other obstacles. Despite fibromyalgia being an obscure and rare medical condition, there is deep relevance in understanding the associated lived experience. An empathetic study can bridge gaps in understanding pain narratives, conveying subjectivity, somatic forms of knowing the self, and finally how the individual becomes conscious of changing norms through the felt sense. In sum, this research aims to understand how individuals subliminally renegotiate the normativity of practice and experience after the onset of a life-transforming illness.

Considering the need to examine the lived experiences of individuals with chronic illness, it first helps to understand the somatic and medical context. Fibromyalgia is generally characterized by symptoms such as fatigue and widespread musculoskeletal pain (“Fibromyalgia | Arthritis | CDC” n.d.). The symptoms experienced are inconsistent due to its’ high comorbidity rate with other complex chronic illnesses however, some listed common symptoms may include sleep disorders, brain fog, TMJ issues, IBS, mental health concerns, etc. (“Fibromyalgia | Arthritis | CDC” n.d.). This study seeks to connect with fibromyalgia patients however it is assumed that all interviewed individuals would have a unique set and relationship of symptoms and comorbid illnesses; some observed examples in the study included chronic fatigue syndrome (CFS), postural orthostatic tachycardia syndrome (POTS) and others. These diverging experiences are unified by fibromyalgia. However, it is acknowledged that the varied differences further nuance research considerations as each symptom and unique life experience informs people of their disposition.

Despite the listed symptoms and comorbidities, the current diagnostic criterion is informed by two proposed scales: The Widespread Pain Index (WPI) and the Symptom Severity Scale (SS) (Galvez-Sánchez and Reyes del Paso 2020). The WPI takes note of 19 possible pain

afflicted areas and the SS is the calculated score for other relevant diagnostic considerations such as fatigue and cognitive issues (Galvez-Sánchez and Reyes del Paso 2020). This diagnostic hypothetically provides consistent measurement to allow clarity in the diagnosis process. However, as of yet, fibromyalgia lacks any observed objective biomarkers. Diagnosis continues to be concluded through exclusionary factors. There is a growing need to account for understanding that includes cultural, environmental, psychological and other myriads of ways in which an individual's experience informs and influences an illness. For example, there is growing evidence that a history of trauma correlates with the onset of fibromyalgia or that certain individuals are predisposed due to a complex history of inflicted stress (Bohn et al. 2013). Despite the evidence of fibromyalgia's relationship to psychological trauma, the current literature hasn't been able to identify its' etiology sufficiently. There is a multitude of possible origins in addition to previous exposure to trauma, stress and disease such as possible genetic predispositions (Liptan 2016). That said, the definite uncertainties inform how individuals conceive of their illness experiences. Furthermore, this research does not seek to be medical research or advice in any shape or form but rather to describe and understand fibromyalgia narratives that are informed by somatic and social realities.

Fundamentally, the subjective qualities of fibromyalgia debilitate its acceptance and comprehension in medical and other social spheres at large. The lack of coherent objective biomarkers and opposing medical theoretical perspectives in addition to the subjective interpretations of the illness allows for stigmatizing fibromyalgia and people (Galvez-Sánchez and Reyes del Paso 2020; Jackson 2005). To understand the fibromyalgia experience, this study seeks to develop an argument through in-depth ethnographic interviews with a small group of individuals. This will most definitely include an emphasis on qualitative accounts. The goal is

not to generalize the analysis derived from this small group but to continue to build comprehension of the illness experience in depth. To garner depth into the research topic, interviewing a small focused group will yield longer dialogues and will capture fibromyalgia-related pain narratives better than other methods. Through such measures, this research endeavor shall generate an understanding of potential schisms between the individual and their background, between normativity and pathology, and between life prior to onset and life post-onset of illness. In contrast to literary theorists like Elaine Scary (1987), who see pain as a disorganizing rupture in people's lives, this research explores how pain as a symptom potentially structures personal narrative, creates meaning, and shapes lifestyles. These insights will be informed by a phenomenology of liminality, an anthropological understanding of embodiment, and through George Canguihelm's writings on norm and pathology.

### **Theoretical Framework**

To begin, fibromyalgia, like other illness concerns, begins its journey with the afflicted individual. It is this individual that deems a condition tolerable or intolerant. Thus, this research assumes that the patient's subjective awareness of their symptoms inducts them into an abnormal state. This may appear as a trivial aphorism however, within the described experiences from interlocutors, the chronic illness experience is fraught with doubt and stigma. Canguihelm vehemently states that pathology is deemed as such only through reference to a priori knowledge of a corresponding normal state (Canguilhem 1978). One's history of experience is vital in contributing to one's conception of their illness status. This disruption in the course of one's life begins with the felt sense, not the official diagnostic processes typically observed in biomedicine. Fibromyalgia patients often go long periods without diagnosis due to the nature of

the illness, being that no clear biomarkers often leave doctors in doubt and confusion.

Canguilhem states: “would it not be appropriate to say that the pathological can be distinguished as such, that is, as an alteration of the normal state, only at the level of organic totality, and when it concerns man, at the level of conscious individual totality, where disease becomes a kind of evil” (Canguilhem 1978). Despite the lack of biomarkers, there is a transformation in the body that medicine is yet to uncover. Current theories stipulate that fibromyalgia’s occurrence has relations to processes associated with the central nervous system called ‘central sensitization syndrome’; central sensitization is proposed to be a bodily state in which the central nervous system amplified sensory uptake thus, pain and other negative bodily responses are heightened to a discomforting degree (Fleming and Volcheck 2015). That stated, the transformed somatic situation becomes apparent and gains validity in the conscious deliberation of the affected individual. The fibromyalgia patient becomes vividly aware of their abnormal situation despite the lack of observed clinical evidence. The fact of illness and associated symptoms is only made evident through its’ associated subjective perspective.

Canguilhem’s beliefs informs that the condition of normal and abnormal are not fundamental givens but rather contextually constituted as according to one’s history and evaluation. Therein, there is an embodied regime of values. The sensation of localized somatic pain or fatigue or even cognitive delay is quite vividly and viscerally accepted as disturbing and disrupting and forces the afflicted individual to confront something abnormal. These somatic sensations, especially acute pain responses, are not necessarily negative features. In fact, acute pain responses are functionally valuable for organisms to ignite appropriate actions in response to whatever environmental concern (Coninx and Stilwell 2021). When it comes to fibromyalgia, however, the associated pain and other symptoms are recognized as chronic features in one’s

changed narrative. These chronic symptoms are obstacles to the desired life that one can lead. Canguilhem defines the normal man as being capable of establishing new norms, including organic ones (Canguilhem 1978). The obvious issue for chronic illness sufferers is that their lives are delimited by chronic ailments that ensnare their day-to-day happenings. If fibromyalgia has a distinct relationship to stress as recognized by one's nervous system, then the natural response is for medical professionals and patients to assess treatment 'holistically' or in other words to decrease stress and encourage relaxation through conventional and alternative means. Presumably, coping with the stress of fibromyalgia may lead to positive improvement however, the origin of illness remains uncertain. Naturally, this proposes the myth of the chicken and egg conundrum as one may ask if the somatic symptoms sustain the illness state or that the psychological distress perpetuates the somatic symptoms; however, this is a reductive perspective considering we are met with a network of factors that buttresses the fibromyalgia condition (Häuser and Fitzcharles 2018). Furthermore, the reason for the onset of a chronic illness may be irrelevant to the reasons why a chronic illness state is sustained across time (Coninx and Stilwell 2021).

The fibromyalgia illness experience fundamentally transforms one's narrative and life trajectory thus, forcing the afflicted individual to embark on a journey to reconcile and integrate the experience into their subjective lives. We can presume that fibromyalgia is not isolated from the afflicted individual's surrounding environment and lifestyle choices. Fibromyalgia makes acute pain unbearable and subjects disorientation as norm. This norm does not function in isolation. The biological benefit of pain lies within recognizing the organism's affordances according to the interacting contextual environment. Coninx summarizes, "under optimal conditions, as the subject dynamically interacts with the world, the felt tension of a bodily

imbalance fades and the field of affordances returns to a default stance” (Coninx and Stilwell 2021). In reality, this optimal process may be more complicated as evidenced by the existence of fibromyalgia. The confluence of fibromyalgia symptoms forces the subject to recognize one’s desired trajectory, the cessation of illness. Canguilhem succinctly lists that illness and health are processes and these biological processes do not recognize reversibility (Canguilhem 1978). One interacts with their environmental conditions through polarized acts. This polarity recognizes and qualitatively attributes facets of experiences as acceptable or intolerant. Thus, disease is acknowledged in this trajectory. The illness is realized and now the afflicted patient is forced to reconcile this reality. There is no return to a previous normal; at best, health transitions to a new biological norm in which fibromyalgia ceases to be.

What is evidenced by these theoretical assumptions is that the human being is imbued with an embodied a priori perceptual structure. This premises a need for a phenomenological approach that collapses the pervading mind-body dualism that is often chained to social science research. This also premises that the associated controversies and myths of fibromyalgia should rather be examined through embodiment as the analytic. Csordas outlines the anthropological paradigm of embodiment: “this approach to embodiment begins from the methodological postulate that the body is not an object to be studied in relation to culture, but is to be considered as the subject of culture, or in other words as the existential ground of culture” (Csordas 2002). This paradigm promotes the analysis of fibromyalgia narratives not in relation to the individual’s contemporary interactions but rather suggests the reported illness experience is the foundation upon how individuals formulate their understanding of themselves within the context of their culture. Considering the paradigm of embodiment, the individual’s qualitative conclusions of their fibromyalgia symptoms coalesce to later become objectified as sickness or as abnormalities.

Csordas continues, “phenomenology is a descriptive science of existential beginnings, not of already constituted cultural products” (Csordas 2002). Despite this article’s position being that fibromyalgia is validated and concerning, the ascribed object of fibromyalgia is culturally constituted through the confluence of medical research, patient-doctor interactions and foremost the patient’s embodied illness in accordance with environmental interactions. The afflicted individual perceives a multiplicity of signs that shepherds the eventual inference of an abnormal bodily situation. The goal of the paradigm is to capture how perception begins amid arbitrariness and indeterminacy as per how it constitutes throughout the cultural milieu (Csordas 2002). A phenomenological analysis not only yields insight into the internalized contents of the behavioral but also can reach first-hand insights into the perspective of the subject in discussion by a close study of how they discern and make sense of bodily signs and symptoms—a process of semiotics. Charles Pierce’s semiotic phenomenology allows for a particular vocabulary to articulate embodied interpretive processes. Linguistic anthropologist, Susan Gal, has utilized Pierce’s theories to explicate differentiation among ideologies in the formation of political subjectivities (Gal and Irvine 2019). However, insights drawn from their analysis of signs can also be applied to how processes of differentiation among patients in the formation of illness subjectivities. In particular, it is helpful to approach the symptoms of the body as indexical signs, which not only embody a feeling (what Pierce calls an iconic sign) but also may index or point to processes of illness or healing. These signs are interpreted by individuals within a perpetual interpretive process; Gal posits that such “conjectures posits an axis of differentiation, of creating a schema of qualitative contrast both for indexical signs and for what they are taken to represent” (Gal and Irvine 2019). Sign interpretive processes (including the experience of symptoms) form a continual subjective experience through the uptake of stimuli. This is consistent with illness

experiences of patients as they continually acknowledge and process somatic symptoms. Be it in spoken language or illness experiences, semiosis is an embodied process. These differentiations they experience in bodily changes are qualitatively contrasted to indicate a distinction between normal and abnormal dispositions. This indexical sign can shift to become an icon as in a great moment of localized pain, or the same localized pain sign can be recognized as indexical of an abnormal state or even more specifically of a multiplicity of possible illness processes. Gal and other linguistic anthropologists refer to this phenomenon as rhematization (Gal and Irvine 2019). In the case of fibromyalgia, pain and other bodily signs are indexed of increasing (or decreasing) abnormality. This interpretive pattern is consistent in all interpreting individuals, this includes the chronic illness population.

Fibromyalgia as an experience is only recognized through an embodied subjectivity. To begin, there are multiple possibilities in which a patient may experience themselves through the body. Some delineated embodiment dimensions within the field of phenomenology account for affective dimensions of embodiment, functional dimensions of embodiment, a material dimension of embodiment, or even a social dimension as well (Grünfelde 2018). These examples of dimensions of embodiment are not necessarily independent of one another. All potential possibilities of embodiment inform the fundamental experiences of the afflicted fibromyalgia patient. For example, there is an imbued agency with the body. This agency is dramatically affected by symptomatic limitations. The felt sense inevitably outruns the possible communicative means resulting in confusion and misunderstandings of the visceral fibromyalgia experience. The given felt sense of the illness is never adequately conveyed due to the limits of language. This felt sense in the form of fibromyalgia symptoms is also recognized as a subject that is uniquely owned by the perceiving individual as well. One experiences the body as a

feeling and acting subject and also as a felt and observed object thus, the dimensions of embodiment are inevitably intertwined (Grünfelde 2018). Furthermore, what is fundamental to being affiliated with fibromyalgia and illness is disruption. It is a disruption of a chronology of desirable imagined events. In phenomenological discourse and embodiment paradigms, the conscious mind is inseparable from the agentic body (Grünfelde 2018). Considering this, the perceived fibromyalgia somatic symptoms and their associated life experiences bring forth an understanding of self that is inseparable from the mental state of the patient. Thus, this union between body and world endows one's worldview with meaning through perception and movement (Grünfelde 2018). The fibromyalgia experience prior to any tangible steps towards healing is disunion. The experienced afflictions within the explored phenomenological dimensions heed way for the subject to become alienated from their body; to become alienated from the social sphere and even former presupposing conceptions of their world and culture. Canguilhem's theory premises: "the state of health is a state of unawareness where the subject and body is one" (Canguilhem 1978). Fibromyalgia demands attention. Fibromyalgia courts disunion that results in the subject's conclusion that they have become overcome by an illness. Illness disrupts this fundamental union and thus brings forth a realization of transformed and ridged chronic organic norms.

The confluence of transforming embodied and social norms recognized by the fibromyalgia subject begets a liminal status. The qualitative judgement of the illness afflicted subject thus has an initiatory quality. The confluence of embodied somatic and psychological signs alongside social and functional signs coalesce to characterize the subject as a chronic illness struggler. The social repercussions of fibromyalgia are recognized in the unending diagnosis process in which communication is stifled by the lack of objective biomarkers. In

addition to disrupting social relationships and biological normativity, illnesses are experiences that disrupt the very sense of self, including how one orients and conceives of themselves in relation to time and space (Coventry, Dickens, and Todd 2014). In fibromyalgia patients, the embodied suffering of mental and physical fatigue, anguish, and heightened disorientation to stimuli such as even exposure to light, inducts individuals into a liminal status. Liminality was first formulated by Victor Turner, following Arnold van Gennep's writing on ritualistic practice. According to Turner, liminality is the hypothetical stage in which a certain threshold is met, upon which the individual is transformed in the process of a salient ritual. Turner writes: "liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial. As such; their ambiguous and indeterminate attributes are expressed by a rich variety of symbols in the many societies that ritualize social and cultural transitions" (Turner, Abrahams, and Harris 2017). Turner's conception is interlaced with his social functionalist perspectives. Perhaps that is accurate within ritual contexts however, to examine fibromyalgia accounts, Turner's conception is best paired with Canguilhem's exploration of norm and pathology. As such, liminality can then utilize for a diachronic analysis of illness experiences. This is relevant in the chronology of disease; the individual is met with the onset of fibromyalgia, thereby separating the individual from their former state due to transformed social and embodied norms. Turner describes the initial phase as a symbolic separation or detachment of a group, thus the individual begins their rite of passage or liminal status; through this lived and metaphoric passage, the individual is then reagggregated and reintegrated into the pre-existing social structure with a transformed social role (Turner, Abrahams, and Harris 2017). Reexamining Turner's exploration of rituals and functional role changes through Canguilhem, one can then recognize the induction to a liminal status in

fibromyalgia patients is due to the confluence of embodied symptoms and the associated social interactions in biomedical and at-home contexts. The ritual in this case is not a dramatized interpretation with an overt function but is initially imbued with indeterminacy and abeyance. Turner continues and suggests the concept of liminal personae or “threshold people”; these are individuals suspended in an ambiguous state that eludes classification (Turner, Abrahams, and Harris 2017). This is eerily observed in the diagnosis process for fibromyalgia accounts. Diagnosis is difficult due to the ambiguous and indeterminate points of fibromyalgia. Thus, liminality is recognized as a social status in addition to an embodiment of transformed somatic norms. The existence of threshold people then naturally allows for a community or specifically “communitas” according to Turner; this communitas exists as a communal recognition of individuals equalized upon a liminal plane (Turner, Abrahams, and Harris 2017). Naturally, congregations of chronic illness support networks arise, such as the support platforms where volunteers were recruited for this study; these networks, assuming these theoretical presumptions, unite chronic illness patients under a banner that eludes the structures present in other factions of society.

Liminality, as observed in the fibromyalgia accounts, inhabits both a social and embodied sensibility upon which disruption inspires and cements the patient as a liminal being. Placing disease in the continuum of liminality and the rites of passage implies there shall be a post-liminal state in which the individual is reintegrated and assimilated in their social sphere as a changed individual. This condition may not be apparent in the case of chronic illnesses that may or may not have an established cure. However, liminality is premised upon an inherent categorical shiftiness therefore, a post-liminal state may inhabit a threshold state between being inducted into the liminal state and towards a post-liminal state in the fibromyalgia example

(Brown, Huszar, and Chapman 2017; Jackson 2005). This framework also seeks to establish liminality as an embodied phenomenological disposition as well. Brain fog is one such possible example. Brain fog or “fibrofog”, a common and important reported fibromyalgia symptom, is an example of an embodied liminality. Brain fog is often characterized by cognitive issues with memory and the ability to focus and other mental faculties (Liptan 2016). This cognitive disposition is often described through metaphors to suggest a liminal state; for example, “being stuck in time” or highlighting the perception of apparent ‘strangeness’ or “surrealness” in their situations. Furthermore, liminality is not only premised upon a chronology of an individual transformed by events but also through its lack of being able to be categorized into conventional societal constructs such as medically accepted diagnoses (Jackson 2005). This is evident for fibromyalgia and other chronic illnesses due to their indeterminate origins thus, highlighting a gap in which chronic illnesses are outside of current biomedical knowledge. Considering the liminal nature of illness, fibromyalgia becomes stigmatized in both embodied and social terms. Stigma informs the afflicted individual and the people who interact with fibromyalgia patients, thus this article will also explore how stigma recursively reinvigorates and informs the liminal status. Canguihelm explicates this phenomenological status through his theoretical position:

An anomaly manifests itself in spatial multiplicity, disease, in chronological succession. It is a characteristic of disease that it interrupts a course; in fact it is critical. Even when the disease becomes chronic, after having been critical, there is a past for which the patient or those around him remain nostalgic. Hence we are sick in relation not only to others but also to ourselves. (Canguilhem 1978)

## **Methodology**

This research was developed through in-depth ethnographic interviews. This pursuit will emphasize qualitative accounts to gain depth rather than a general understanding of personal accounts. This method will benefit insights into illness experiences by unveiling narratives and accounts that showcase the values of individuals. All my listed questions aim to be open-ended. The questions should give way for answers that coalesce to indicate attitudes and values within personal narratives. These interviews were loosely structured and planned with a list of questions however, interviewees were allowed to lead discussions and bring forth anything they deemed relevant. The set of questions loosely articulated one's comprehension of their narrative with illness. Needless to say, as an interviewer and as a separate person, I cannot conceive of the visceral responses of one's unique unfolding narrative however, being an empathetic listener allowed this research to build its reasoning upon logic endemic to particular fibromyalgia narratives.

The study included eight individuals with a myriad of chronic symptoms who have one way or another been identified with a diagnosis of fibromyalgia. The desired goal is to have a dialogue with my interlocutors over six weeks. Each individual partook in an initial interview and throughout the weeks some conversation threads with interlocutors remained open via text for further questions and discussion. The time in-between interviews and discussions informed the direction of my research. There was a preliminary literature review however throughout six weeks the themes and research interests remained malleable according to received ethnographic data. The initial set of interlocutors was contacted through an online support community on Discord (which was discovered through Reddit). This community is united by a common worry and diagnosis of fibromyalgia but also other unique conditions and situations. This is a rather new phenomenon that allowed for access to potential participants. However, as later discovered,

many of these online forums understandably prevented research to be conducted to protect the community from unwanted attention. Due to this common rule, I found my interlocutors through direct messaging users and requesting interviewed interlocutors to recruit others if they desired to do so. I acknowledge that there is a particular uniqueness ascribed to this online community as Discord support groups and other online forums appear to be a rather recent phenomenon and may incur critiques of whether or not my interlocutors are representative of the study I seek to accomplish. Some communities harbor more positive rhetoric whereas other online communities, albeit less robust in the community aspect, continually ruminate on negativity. This is important to note however, my focus solely remains on the progressing effects of somatic change on subjectivity, not discursive sociality through online mediums. I hope to gather relevant data that not only paint narratives with empathy but also allow for analysis of subjective experiences regarding cultural and individual conceptions of chronic pain that are associated with fibromyalgia.

For the sake of research consistency, this study sought to only interview individuals who had been diagnosed with fibromyalgia. However as acknowledged in earlier statements, fibromyalgia symptoms vary significantly from patient to patient and the illness is comorbid with other stigmatized conditions such as chronic fatigue syndrome and mental health concerns, namely anxiety-related disorders. The diagnosis requirement, therefore, did not exclude the likely comorbid medical and mental health concerns and social dispositions. The research and recruitment process are predicated upon the assumption of intense variety in symptomatic expression and life experience. Furthermore, the recruitment process desired a mixed variety of people, however, as fibromyalgia is statistically more common in females. What was unanticipated was that in the encountered online circles where recruitment took place, there was

a significant group of non-gender conforming individuals; some took part in the study however, only one person shared that their gender identity and fibromyalgia experience are related while all others believed their gender identity and illness experience were unrelated phenomena. More specifically, three of the eight interlocutors identified as women while the other five described themselves to be non-gender conforming in some form or that they were still exploring their identity. All individuals were 18+ and remained anonymous for the final research submission for liability reasons.

All interviews were either conducted through zoom video chat or text on discord. Zoom interviews were recorded and transcribed through Otter.ai, a transcription application. Transcripts were later edited as needed for later analysis. Since the interviews roughly followed a sequence and had consistent questions, interlocutor answers were easily grouped in sets for interpretive analysis. The questions were loosely based upon a presumed chronology of events: onset of illness, the events during illness and reflection of illness. Questions were asked loosely and picked based on observed conversation direction rather than strictly following a particular itinerary. The final result is this research analysis.

### **Ethnographic Analysis**

This project understandably had unanticipated obstacles. Any academic project was met with suspicion when breaching into online fibromyalgia support circles. Initial recruitment efforts garnered warnings from the platform moderators. People afflicted by fibromyalgia, chronic fatigue syndrome, and other chronic illnesses remained wary of judgment due to stigma. Since stigma is inextricable to living with 'invisible' illnesses, people safeguarded themselves. Moderators on these platforms banned all solicitation. These warnings were established to

protect people. In addition, pain and fatigue simply prevented many individuals from actively wanting to engage with this study.

In this effort, a diverse group of interlocutors contributed to the research. There were 10 interlocutors who volunteered to be interviewed, of which eight contributed extensively while the others provided some interesting points. The limiting factor may have been due to the initial inhibition and safeguarding prevalent with stigmatized or fatigued individuals. There were more volunteers and invitations however, this latter group withdrew their engagement likely due to the listed possible frictions. All in all, being afflicted with chronic illness has subjected these individuals to consciously or unknowingly shift their norms and behavior on communication and camaraderie.

#### Embodied Signs:

Illness first and foremost informs the carrier. Abnormalities are recognized through a confluence of semiotic signs through an embodied a priori perceptual structure. The body naturally evaluates pain and other discomforts. Fibromyalgia is the eventual title bestowed to an embodied array of symptoms and signs in the lives of patients. The very first signs of fibromyalgia become evident through an array of bodily signs, often ambiguously perceived to be unrelated and isolated concerns. Eleanor, a young Australian woman finds herself afflicted with fibromyalgia. After a year of endless medical visits, she found her diagnosis and proper treatment. Despite her constant fatigue and sensitivities, she is exerting her energy in preparation for her desire for a Ph.D. to study online communication and digital trends in internet humor. She reflects on her body: “I always had like, weird things about my body that like nobody could really explain and like, just didn't add up.” Despite the apparent ambiguity ascribed to her

“weird” bodily responses such as how she later describes and ascribes her consistent clumsiness from childhood as an early precursor sign of something perhaps out of the ordinary. Hence, when one reflects one discovers a possible unveiling illness narrative. Clumsiness and weak palm strength in her case are no definite medical signs of impending illness however, Eleanor characterizes these as odd quirks associated with only herself. She continues describing how her somatic quirks would surmount to become an obstacle in her academic efforts during her honors thesis. She states: “But then in 2020, I started my honors thesis and then obviously COVID hit. And then I started getting really, really sick, like, abdominal pain at first that just got worse and worse. And then joint pain, and then all of the sensory things. Yeah, and I just got sicker and sicker.” Once again, there is an inherent ambiguous facet to her history. Her symptoms gradually coalesce to become a major obstacle. Despite the ambiguity, one cannot contest that this gradual sickness has an inherent negative value in the life of the subject. The former clumsiness may not have incurred serious negative judgment from the affected individual however, in the unfolding context of her abdominal pain during her academic projects, the unrelated somatic incidences indexed a warning. It helps to examine the illness experience as embodied signs that index, a sign that indicates a causal relationship. Eleanor’s discomforts were pertinent warnings of her health status. Something was abnormal. Eleanor’s situation was not her normal disposition; something was changing. These discomforts index abnormality in the case of an unfolding chronic illness, this threat remains to be an ambiguous figure until explicated through further interpretation. More specifically, Eleanor’s embodied signs were self-referential; these were somatic signs that refer to the body itself through its own natural language (Busvold and Bondevik 2018). It was a part of the body’s internal communication via fatigue, pain and other

worrisome signs. This interpretive process is internal, and spontaneously recognized by the subject. This embodiment affirms that beliefs were existentially steeped within the body itself.

Eleanor was propelled to search for a diagnosis. The label of diagnosis legitimized the embodied signs as a unified object for retrospection. Fortunately, she had received her fibromyalgia diagnosis after a year in addition to potentially having other medical concerns, one being postural orthostatic tachycardia syndrome (POTS). This was a significant problem in the Australian heat for Eleanor. Her array of symptoms of fatigue to heat sensitivity to joint pain to other discomforts coalesced to justify and warrant a diagnostic label. Her combination of symptoms proved to be dangerous. Eleanor worked with dogs and other pets but her illness proved to be an obstacle. She shares: “I was working for a pet sitting and dog walking company, which involves like, hours of walking a day. Which got to be a problem especially and that’s when I started fainting and like, so it was getting dangerous. y’know. I was alone with dogs and there was a risk of me fainting like, that’s pretty bad. Hence, these examples of embodied signs referenced an apparent regime of values that qualitatively differentiated desirable and undesirable states of health. Thereby, legitimizing and turning the array of symptoms into a unified object to reflect upon. In other words, being diagnosed with fibromyalgia collapses some of the initial ambiguity by drawing connections among a constellation of seemingly irrelevant symptoms. However, this clarity is short-lived due to the uncertain origins and multimorbidity associated with fibromyalgia and other chronic illnesses such as POTS in this case. As a result, these symptoms that incur negative value judgments due to pain, ambiguity and uncertainty develop and informs a conscious subject of her situation, yet again, the threat is supposedly shielded by the unknown etiology. Eleanor then shares: “I’ve always been really extremely sensitive to the heat and like, affect more affected by it than anyone else and like, people just

thought I was being dramatic. And I was like, Oh, I guess I guess I'm just weak.” The common trend appears that these signs were initially perceived as somatic discomforts however, as time progresses, the illness signs incurred further psychological discomfort due to confusion and disorientation. That is not to proclaim that multimorbidities with no known etiological origin are the sole characteristic of an embodied disorientation. Each symptom, each social and structural sign, and each illness brings a complicating factor in the therapeutic process and semiosis of the afflicted individual. The consequences of each sign allow for the likely chance to separate the union between ego and body.

The visceral and subjective qualities of illness experiences court the mind and body. The confluence of these signs induces a different lived reality as compared to life prior onset of these bodily signs, thus affirming an embodied liminality for fibromyalgia patients. The unfolding chain of events is an unfolding history of the individual that has inducted a changed lived reality in need of adaptation or compensation. Serafina from Italy describes that her problems began when they were 12 years old. They were having trouble with tinnitus, a chronic ringing in the ears, for no apparent reason. This nuisance went on until in their mid-teens. Then the problems shifted to debilitating headaches, at times preventing them to smile or speak. The pain symptoms became prevalent in other parts of their body with no apparent connection leading them to explore solutions. Serafina’s symptoms prevented them from outings with friends. Thus, they felt very isolated. At this point fibromyalgia hadn’t been diagnosed; some doctors attributed the pains to dental bruxism or also known as teeth grinding. Which later, Serafina describes how their body potentially misaligned itself after the onset of the initial craniofacial issues as means to compensate. This compensatory factor unveils a conundrum. Due to one’s biological individuality, it is often difficult to conclude the illness origin without considering all potentially

mitigating factors such as genetics, epigenetics, etc. The matter is, the origin is often indeterminate however, one can generally assume complex and sustained chronic illnesses are compensatory by nature, as evidenced by accounts of lived experiences; the body naturally attempts to correct the pathological arrangement as a result, further affirming a pathological somatic pattern. Change is exclaimed by the visceral phenomena. This is concluded through what the individual subjectively acknowledges. The illness experiences as understood through these fibromyalgia afflicted interlocutors unveil an embodied capacity of human experience. Upon this understanding, liminality is recognized as an embodied faculty in addition to its association as a social status.

#### Polemics and Norms:

The initial somatic signs are polarizing. The polemic incites and indicates adapting to new circumstances. This isn't isolated from one's environmental context as well. Previous norms are made null due to recognition of an embodied reality. As a result, the felt sense becomes the primary negotiating factor in how one hopefully reestablishes a sufficient lifestyle. This felt sense is mediated by the heightened and disorienting symptoms of fibromyalgia. Rachel, an adventurous American woman who used to plunge into risks without worry describes how her chronic illnesses suddenly transformed her life. She moved from pain clinic to pain clinic however, since her illness lacked a medically authenticated biomarker she felt as if "she fell through the cracks". Her illness alarmed doctors for being inconsistent. She believes many of the doctors she had seen had dismissed the illness as it was abnormal according to medical standards. The nature of an invisible chronic illness is stigmatizing and garners confusion on who may be the right person to treat such problems. This confusion is inherently polarizing; it is

alarming to the afflicted individual. Unfortunately, in this example, she describes how the abnormal clinical signs and the preconceived medical views had allowed a second complex illness to go unnoticed, chronic fatigue syndrome. Not only has she had to deal with the stigma and pain associated with fibromyalgia but also deals with the key characteristic of CFS, post-exertional malaise. The consequences of post-exertional malaise mean that any directed bodily exert can result in debilitating fatigue that may take days or even months to recover. Unlike other chronic illness situations where one returns to a default illness situation, post-exertional malaise may further debilitate and deteriorate the illnesses and fatigue to the point where some need feeding tubes and other support. For this interlocutor, this means exercise and other fruitful and healthy acts can paradoxically hurt their health in the long run. As a result, she has become incredibly conscious of the things she partakes in; pain, brain fog, and fatigue dictate and allow and construct her daily habits. She cannot work for the time being and had to relinquish her passion for video games to a certain extent. Prior onset, she described herself as hardworking and an honors student during her college years. She tells me her hand-eye coordination and reflexes had become comparatively sluggish since fibromyalgia and CFS. Relinquishing is endemic to the illness experience to accommodate undeniable norm changes in the body.

The unfolding of fibromyalgia narratives is propelled by polemic social and embodied signs that must be integrated into one's transformed lifestyle. Furthermore, the symptomatic experience beckons questions of affected mental health. Rachel relinquished her career and passion for the time being. She engaged with moderating online gamer servers to stay engaged. According to her, this deteriorated her health and wellbeing. The caveats of her diagnoses meant that exertion of any sort would paradoxically deteriorate her health even when she engaged with things that made her days pleasant like her passion for video games. Ultimately, prolonged

illnesses of any sort often come with mental health concerns. The issue with mental health is at times it is described to be the cause of chronic somatic symptoms or at least the associated stress of depression or anxiety sustains or further hurts a chronic illness. Rachel shares: “It's almost a miracle if you don't start developing some sort of mental health issues because you're dealing with a great deal of constant suffering and so, it is a pet peeve of mine... when people try to attribute it's a chicken and egg problem”. Once again, indeterminacy pervades etiology.

Misunderstood and misattributed hypotheses and explanations of fibromyalgia encourage cognitive dissonance and inaccurate depictions of people's lived experiences. Letting go is an inherent and imperative reality for fibromyalgia afflicted individuals. Each mental and physical step is novel as one essentially relearns what is acceptable in their life as the consequences of a misstep are not a good outcome. Prior illness onset, this particular individual lived adventures, having moved across the United States multiple times. Now she shares: “I had so much energy, there's so many things that I could do. And so, and that all that all changed. I just, I can't even I don't even have the energy to do basic life tasks. I can't even not only can I not work, I can't. I can't even be like I can't stay at home. And like, even at home, I can't do. I can't take care of the house. You know what I mean? Like the traditional like, cleaning and laundry and, you know, groceries and shopping that's all of us kind of have to do. Those are things that I would love to be able to do, but I can't, you know”. Her sense of agency has been fundamentally disrupted; her illness unveiled new normative parameters that she is forced to consider and reconcile. In doing so, one's practice and day-to-day life are constantly renegotiated. One has to relearn what is appropriate for them since their previous lifestyle can no longer be sustained. However, this has not meant it was necessarily halted completely. Rachel uses her ability to read and summarize difficult academic medical journals to help people from online support groups. Thus, it appears

that chronic illnesses first appear as a discontinuity in one's life until one integrates a possible origin or finds acceptance. In the experience of fibromyalgia, the unfolding events are marked by polarizing signs that manifest in bodily functions and social interactions that sometimes suggest persistent normativity and other times point to stigmatizing difference. In this sense, multiple axes of differentiation are present, based on embodied experience and social norms.

#### Connection and Liminality:

Fibromyalgia can be debilitating and requires strong support networks, however, conveying the fibromyalgia experience remains difficult. At the onset of fibromyalgia, an individual is awakened to a different world prior onset. Comprehension of this novel felt sense requires renegotiating behavior and conceptions of one's worldview. The embodied sensations of stigma and illness induct a person into a particular liminal status. They achieve a felt sense that is betwixt upon a threshold. This liminal status is not only a chronological event that ideally includes reintegration to their former social networks or 'former lives' but also a general embodied capacity of human experience. One enters liminality within the stages of ritual to later be reintegrated into a culture but one embodies this liminality due to the influx of sensorial information. It is key to recognize the body orients itself within time and space according to the influx from the senses. This stability is jeopardized with the advent of fibromyalgia and other illnesses. The highly stressed body is impeded and smothered by threats in the form of illness symptoms; the individual is impeded by an imposed illness trajectory. All in all, the conscious person's world is rendered incomprehensible in a multitude of ways through an embodied disruption. One's perceived life trajectory and narrative necessitates reconsideration after onset. As a result, the embodied liminality is disorienting in relation to perceiving oneself in their

unfolding lives and the places they inhabit. Furthermore, the lived experience always inhabits more than what is communicable. Afflicted individuals inevitably have difficulty conveying a visceral phenomenology to family, friends, and medical professionals, further establishing this liminal status.

Exploring liminality is difficult without considering a personal account. One individual based in Japan, Hiroko, describes their difficult story. This person began with intense gastrointestinal issues that gradually worsened over time. Echoing other people's accounts, Hiroko shares that doctors were bewildered by the situation and weren't able to alleviate the issues. All the medical tests couldn't provide evidence of any biomarker, leading this person's mother to assume that the issue was psychogenic in origin. Despite great efforts, working with a psychologist did not yield much alleviation of the pain symptoms due to the patient's mother and therapist's preconceived misconceptions. That is because the pain was not imagined nor necessarily psychogenic. The patient's mother and therapist believed that the pain was imagined and the fatigue was fictitious drama. The stigma surrounding the patient's undiagnosed illness experience alone affirmed a liminal social status. Not only did the embodied sensations disorient the trajectory of their lifestyle but also the monotonous medical examinations and misconceptions affirmed a life that was neither normal nor comforting in any manner. This fundamentally deteriorated the communication and relationship between the mother and the patient. Since validation was difficult to come by, this patient and many of the other interlocutors, sought out help through support groups such as the fibromyalgia support groups on Discord and Reddit. It was through the support from online networks that this individual was able to find a diagnosis and begin treatment for fibromyalgia. This turn of events and confirmation of illness, however, could not alleviate the strain between mother and child. The

difficulties in communicating and disbelief lead to serious altercations and obstacles to returning to a prior relationship norm. The mother's responses rapidly became possessed with bursts of anger leading outsiders to speculate an abusive situation. In any case, the miscommunications forced the Japanese authorities to get involved further igniting possible resentment and confusion. Ultimately, the interlocutor's mother disowned them and blamed them for the pitfalls of being afflicted by a very real illness called fibromyalgia. Fibromyalgia in Japan is a relatively unknown condition, and as a result, support was difficult to acquire. The Japanese authorities place this individual in a facility for people with intense mental illnesses. This interlocutor, however, did not have a debilitating mental illness so inadvertently their status as a liminal being was further affirmed. This story illustrates the strangeness and surrealness that can be associated with liminality in illness contexts. The patients in the facility had to be socialized and retaught self-care; they too were hypothetically in a liminal state; however, the shared examples demonstrate that each embodied liminality is unique to the subject. liminality is consistently predicated upon a disarticulation of a former status. Often the liminal status is described as being suspended in time and space. This is evident in the existence of an illness and evident in the stigma and confusion that pervades one's network. This is clear in chronic illnesses in that the illness simultaneously suspends the individual and is sustained over time hence, the title chronic illness. The matter of gaining comprehension and hypothetically overcoming the liminal status, according to this research required deliberate meaning-making.

Since the embodied liminality disrupts one's preconceived life trajectory, deliberate strategies are needed to cope and reconstruct a novel narrative that is reconcilable with one's current status. This is also mediated by one's concurrent relationships with friends and family.

Emily from the United Kingdom describes her grief. She had a supporting Christian upbringing that emphasized healing. Growing older Emily has now been exploring who she is with fibromyalgia. She acknowledges her upbringing but also recognizes that right now she's in a space to make decisions on her identity; fibromyalgia inevitably informs Emily's explorations. She describes her grief: "it's a mix of okay, are there things I can do that will help me cope and manage better and increase my quality of life? But then when other people like my family, like, oh, you should do this thing? Because then you'll feel better and have a better quality of life? It's like, No, I feel like they don't get it." Her angst is understandable considering it is likely impossible for another human to viscerally recognize another's pain. However, later she lists items such as spoon theory to alleviate communication gaps amongst her peers. The key metaphor with spoon theory demonstrates that illness-stricken people have fewer spoons or energy to utilize as compared to a healthy family; people with chronic illnesses only have a handful of spoons each day, whereas healthy individuals are nowhere near as limited ("What Is the Spoon Theory Metaphor for Chronic Illness? – Cleveland Clinic" 2021). She explains metaphors are valuable to her because they communicate on multiple levels through an individual's ability to imagine. This communicative strategy also applies to how she speaks about herself. One creative strategy she shared was to imagine the body as a child and the illness and herself as separated parents. The allegorical adults in this illustration need to co-parent to raise a healthy child however, one parent is perhaps paranoid and inflicts undue stress even with the best of intentions meanwhile the other parent is attempting her best to negotiate for a more peaceful family situation. In other words, this metaphor mimics how fibromyalgia represents how it needlessly inflicts duress on the body, which represents an innocent child. The body, as a result begins to compensate and develop idiosyncrasies, symptoms, and pain meanwhile the

conscious patient renegotiates and cares for the body under an unideal stressful home situation. This example illustrates that comprehension can be attained through rendering complexity into segmented metaphors. Though this research does not seek to be a linguistic analysis, it is useful to extract concepts from linguistic anthropology. Linguistic anthropology has long united ethnographic analysis of language and experience through semiotic theory. Specifically, the unified array of indexical symptoms becomes a symbol of fibromyalgia that is experienced iconically, and as a result, this unity of experience is an object that fibromyalgia sufferers reflected upon and modify throughout the course of illness experience. This retrospection and articulation are accordingly a metapragmatic process, a concept borrowed from Michael Silverstein. This metapragmatic approach to illness is often communicated between fibromyalgia sufferers and to others who can then attempt to imagine and develop empathy through enacted metaphors (as suggested by Emily's metaphors). According to Silverstein, every indexical sign, or more specifically, in this case, self-referential indexical signs, serves as a framing character to project context (Silverstein 1993). This metapragmatic process for the disturbing disorientation of illness experience to become organized with contextual meaning. In Emily's case, she imagines negotiating fibromyalgia like a spouse, in doing so, she renders the confusion into something palpable and actionable. Emily achieved her feat through a metapragmatic reflexivity that organized her bodily experience into this metaphorical context. Within linguistic anthropology discourse, contextual understanding is invariably developed through the reflexivity associated with metapragmatic functioning (Verschuereen 2004). In time, these strategies render a foggy life trajectory into something more palpable and allow individuals to at least orient themselves towards something post-liminal by attending to the present or connecting with others, or even imagining a tolerable future.

## Chronic Narratives:

Fibromyalgia steals away coherence in one's life in which one must venture through retrospection to rebuild coherence by integrating details of their history. It is an illness with no clear biomarkers and no definite solution as of yet; it disrupts an individual's trajectory and narrative. One is met with the realization that an illness may have been brewing under their skin years before the visceral symptom. Considering this conundrum, it takes immense mental effort to piece together a coherent narrative. That said this narrative also somehow needs to reconcile that a definite origin is undetermined in current medical research. Inevitably, this pursuit is personal and unique to each afflicted individual. When someone is afflicted by grave illness, individuals are inclined to search for coherence and ask 'why has this happened' or 'why them', 'why me'. Up till now, this research has explicated how embodied liminality transforms how individuals conceptualize themselves in relation to their former lives. Each prolonged chronic illness-stricken individual is forced to update and reconcile the coming signs of illness in their lives. Another point to note is that trauma, genetics, mental health, and others are potential nodes that initiate and uphold chronic fibromyalgia. Caitlin, who has had a long and arduous illness journey, shares her upbringing. She recalls being a healthy child with fibromyalgia being the exception. She was caught with ITP, immune thrombocytopenia purpurae, as an infant. It is an autoimmune condition where the body kills platelets thus, one is at risk of dying from bleeding. She shares that it was severe though she had recovered as an infant and understandably has no visceral recollection. She explained: "So I grew up knowing I was healthy now and had beaten something really bad. I had this feeling of being very lucky because of that, and I do still feel that way. I needed to be a little bit careful because if anyone brushed into my nose it would bleed. I

also took twice as long to get over colds compared to my brother and sister, but overall it wasn't much to deal with." This early illness had changed meanings after the onset of her incoming chronic conditions. However, it would be inaccurate to attribute this as a definite trigger for other possible illnesses. She shares her upbringing of moving around from Canada to rural towns in the United States. Despite having enjoyable experiences in these small towns, she was raised by an emotionally abusive father at the time. Furthermore, her sister also had similar issues possibly signifying a predisposed genetic relationship; her brother wasn't as affected which eerily follows statistic trends of fibromyalgia disproportionately affecting females. Other interlocutors have disclosed trauma and upbringing as possible originators of incoming illness while others share possible viral infections or genetics as common issues. Considering the influx of retrospection, there is significant redefinition in one's history. Seemingly meaningless events all of a sudden are rendered as reasoning points and etched upon an illness chronology. Likewise, Kent, a non-gender conforming individual on the autism spectrum remembers an intense traumatic episode in which a doctor tickled them as a young child. They acknowledge that this may appear random and inconsequential however, they also highlight their predisposed mental health history, autism, and the unusual context of a stranger touching a child hence, creating a potent imprint. Kent grew up with little memory of being healthy. They always recognized their introspective nature and their limitations. Playing sports in the schoolyards wasn't exactly a pleasurable possibility. They already were initiated into a liminal disruption through which meaning had to be carved out through retrospection. Kent admits they will never know the origins of their illness status however if asked to illustrate why it may be the case, they offer this one example of trauma and admits to a possibility of many other confounding variables. In the end, most acknowledge there will never be a way to confirm or negate ideas of how their illness manifested. What matters is

how one chooses to reflect on their history and what they willingly reconcile in acceptance. Caitlin recounts after many years of reflection: “So, initially I felt like the illness had taken away my chance at a good life, but over time I came to realize that my life will always have value... Beyond that, my experiences have their own value in helping other people understand what it's like to be sick. When it was time to apply to graduate school, I decided to make my proposed research about students with disabilities, and was accepted. That made me feel like there are lots of people out there that want to know more about what we are going through.”

#### An Inward Orientation:

Considering how disorienting fibromyalgia has been, it has been founded that the illness experience simultaneously deconstructs fundamental beliefs and provides insights that otherwise wouldn't have been possible to intuitively know. One's unfolding history makes them vividly aware of trajectory and thus there is a need to reconcile meaning with something that is undeniably chronic and even possibly never-ending. That said what would it mean to achieve a post-liminal status for someone with chronic illness? Through disorientation, one gains comprehension of something foreign. Fibromyalgia fundamentally disorders life only to orient it towards a novelty; this orientation is birthed out of the continuity of life prior illness onset. Sierra, whose symptoms have resulted in disability, reminisces their childhood in the 90s as being free and innocent; like an unreal movie, they had once witnessed. They had since then faced a plethora of chronic illnesses and symptoms. Sierra's condition is so complex that it is dangerous due to seizures and debilitating fatigue. They keep food near their bedside and a cup to pee in during intense fatigue episodes. During their worse episodes, they are unable to bathe, move or even swallow solid food. Their family and support network simultaneously supports

them but also misunderstand and thus, marginalize them by dismissal and inconsideration of the chronic symptoms. For example, Sierra's family is nudging them to begin driving however, Sierra fears that brain fog would allow for an incredibly nightmarish accident. Despite all complications, nostalgia, and indeterminate strange symptoms, Sierra states that they would live their life all over again because it made them who they are today. They find that there is at least some intrinsic purpose to their illness. Despite being bedridden during flare-ups, they believe that their experience has given them the insight to share and educate others with. This individual believes their illness had shed light on the gaps in the current biomedicine establishment. This person believes that their illness is a culmination of history, stigma, and culture embodied within them. Their limitations unveiled an unacknowledged presence in their culture.

Sierra holds the current medical models as the culprit to much of the prolonged suffering of chronic illness patients. There is no doubt mainstream biomedicine seeks to heal people however, the existence of unaccounted fibromyalgia patients reflects current treatment and support according to interlocutors. It is expected that sustained illness will affect the mental well-being of people. It deconstructs prior belief systems to the point of nihilism. That beckons questions on how these individuals continue to search for healing and meaning. Trauma had been inflicted on one's psychophysical being through an array of historical and cultural processes along with the individual's inherited traits. These create constraints in one's life so to speak. These limitations are not necessarily abnormal or negative until it has been subjectively deemed so in the advent of fibromyalgia. Therefore, submitting these people to an embodied liminal status. They feel suspended in time and unaware of how that came to be until some coherence is established. This coherence returns agency to the bodies of these individuals through the coherence of their language and the simultaneous acceptance and rebellion towards their bodies.

This does not guarantee success but some do achieve somewhat of a post-liminal status through this inward turning. The disorientation of liminality has the potential to be sublimated as akin to an esoteric status for the individual where they tend to themselves to establish coherence in their chronological life. What arises from this is the potential and rightful return to an embodied agency, to which one can proudly reinstall, reinvigorate, adapt or even enact new norms with one's creative power. One arises with their illness experience sublimated and integrated into the chronology of their life thus, ending the suspension in time and space to the best of their abilities.

### **Conclusion**

Fibromyalgia continues to elude in its treatment and associated experiences. The stigma and the illness' chronic and subjective nature have become a conundrum for patients and biomedicine. One is forced to reconcile and integrate peculiarities into the grander narrative of one's life. It is no longer a question that the associated life experience of fibromyalgia has a fundamental influence on individuals in how they relate to their cultural backdrops and support networks. The reality appears these diagnoses are questionable, not because they don't represent legitimate medical problems. They are questionable because they represent medical problems in an ambiguous fashion, fraught with difficulties for patients. These labels are nebulous to the point a liminal status is bestowed upon an embodied and social level. Through such, affected individuals simultaneously inhabit a marginal space and membership with others suffering from illnesses. Diagnosis, symptoms, and interactions become analytics to reflect upon that enables one to construct the fibromyalgia experience. This immense and inevitable influence will change people for better and worse as observed with interlocutors. The dissolution of a former conception of oneself is the result of transformed social and bodily norms. Canguihelm writes,

“health is life in the silence of organs” (Canguilhem 1978). This acknowledgment recognizes the inherent unity of great health. Thus, we then can acknowledge an embodied unity and its possibility of dissolution. However, this dissolution does not eliminate the human capacity to comprehend and form language in the face of an ominous ambiguity. This dissolution initiates a longstanding internal dialogue among afflicted individuals in which one renegotiates the normativity of practice and experience after the onset of illness.

This a priori perceptual structure intakes the influx of a complex and polarizing environment to orient individuals. One’s unfolding history crystalizes a chronic embodiment. This research finds that liminality is not only status in time but also in embodied space in which one finds difficulty orienting themselves. This is difficult to commensurate, therefore, difficult to diagnose and communicate with the absence of a biomarker. The subjective experience emphasizes an intuitive hierarchy of values; illness is most definitely recognized as negative in its initial experience. However, this liminal status is a turning. Despite disruption associated with illness, one’s existence continues uninterrupted. The embodied individual is imbued with an intuitive capacity and drive to comprehend indeterminate and ambiguous events. Through reflexivity, a metapragmatic reconciliation is possible that creates a new illness subjectivity and organizes the flow of illness experience. Through retrospection, a sense of knowledge is derived and can thus be integrated into the able bodies and minds of others in time.

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## Appendix

### Interview Guide

1. When did your chronic illness begin? When were you diagnosed? How was that process for you?
2. When did you become conscious of your chronic illness?
3. When did you realize something was not right?
4. Did it stop you from doing anything? What have you had to give up?
5. What have you had to refigure out how to do?
6. What little strategies did you develop to resolve, subdue or maybe deal with these symptoms?
7. How did doctors/health professionals explain the future of your condition to you? What did they say would happen over time? How has this fit with your experiences? Were they right so far?
8. How did the doctor break this news to you? Did you find out from a nurse or a doctor? What did that conversation go like? How do other people in your care team / at the hospital talk to you about this diagnosis or this illness?
9. What was the nature of these symptoms? What would they make you feel?
10. What were your thoughts and feelings regarding your symptoms? What about the illness in its' entirety?
11. What are the effects of these particular symptoms?
12. Have you felt anything like this before?

13. How do your friends understand or deal with your condition? Has this changed your relationships with your family? When you're suffering symptoms, how do those around you respond? Do you try to hide your symptoms?
14. How did you try to get other people to understand what you were going through?
15. What was life like prior to onset of illness? How does your life compare to how it was before your illness?
16. Have your attitudes and beliefs changed? How so?
17. Why do you think this happened to you?