

Post Your Journey: Analyzing the Formation of an Instagram Support Community for those  
Living with Fibromyalgia

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B.A., Thompson Rivers University, 2014

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of the Requirements for the Degree of

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in the Department of Sociology

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## **Supervisory Committee**

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by

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## **Abstract**

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Fibromyalgia is a chronic illness characterized by debilitating symptoms such as unpredictable widespread pain, fatigue and migraines. Social support can be a crucial factor in illness management for individuals living with this medically contested, stigmatized and marginalized illness. For many, social media is a significant aspect of their daily reality and in this social space, new forms of relationships and communities have begun to form. This study explores the ways in which a new form of support community for fibromyalgia develops and maintains itself on the social media platform Instagram. A mixed-method research design incorporating both a content and semiotic analysis of Instagram posts as well as interviews with participants utilizing the app was conducted to shed light on the ways in which the relatively new phenomenon of sharing illness experience and support occur on Instagram.

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## **Dedication**

*“If [humans] define situations as real, they are real in their consequences”*

-W.I. Thomas

This thesis is dedicated to all the women who are brave enough to greet each day, knowing they must fight their own bodies before they can even consider taking on the world.

## Chapter 1: Introduction

It is estimated that 2-4 percent of the Canadian population lives with the chronic illness, fibromyalgia (Fitzcharles & Yunus, 2011). The syndrome is mostly characterized by widespread pain as well as abnormal sleep, fatigue and cognitive dysfunction and many related symptoms (Fitzcharles & Yunus, 2011). Fibromyalgia is most likely to affect women and the general age range of diagnosis is between 30 and 40 (Fitzcharles & Yunus, 2011; Fitzcharles, Ste-Marie, & Pereira, 2013). From a medical standpoint, fibromyalgia is contested in regards to its cause, symptoms and even existence. Yet the syndrome is still being diagnosed. Sociological research around fibromyalgia has focused on the history of medical development and concepts surrounding the illness as well as the social construction of fibromyalgia.

Sociological literature on fibromyalgia often focuses on the impact the onset of illness can have on an individual through stigmatization, identity shifts, and the inability to do activities the individual once could do pre-illness (Charmaz, 1991; Crooks, 2007; Skuladottir et al., 2008). When an illness is medically contested, it becomes crucial to understand how individuals react as they may not receive sufficient information with the diagnosis and therefore may struggle to come to grasp with their “empty diagnosis” (Madden & Sim, 2006, p. 2966). These findings guided the present study to understand where individuals living with fibromyalgia turn to for information, support, resources or advice while trying to understand their diagnosis and adjust to their illness identity. Considering the growing phenomenon of social media integration into our daily realities, the almost natural progression into looking to social media for illness information or support formed the creation of this thesis. This study seeks to understand if and how illness

communities are formed on Instagram and what motivates users to participate in these communities.

Since its formation in 2010, Instagram has become a major player in the social media landscape, being purchased by Facebook in 2012 for \$1 billion; in 2013 the app grew by 23 percent, while Facebook only increased by 3 percent (Upbin, 2012; Knibbs, 2014). It is estimated that the social media application Instagram is home to 300 million users (Instagram, 2016). Instagram is unique in comparison to its social media counterparts in that to post, the user must upload an image. This is intriguing given that the symptoms of fibromyalgia are often unidentifiable to the naked eye, making it an *invisible* illness. Therefore, this study seeks to understand how those living with this illness visualize and represent its invisibility on Instagram.

This study also aims to examine the ways in which Instagram operates as a platform for community development and maintenance. Given the popularity of the app and the prevalence of stigmatization of fibromyalgia, it is believed that this app may be home to a community of individuals living with fibromyalgia sharing their symptoms, treatment methods and possibly information about the illness unavailable elsewhere.

## **Research Questions**

This qualitative study aims to understand how online support communities for people living with fibromyalgia are formed on Instagram and how users represent their contested illness to each other. The research questions that guide this study are:

1) *How does Instagram, as a social media platform, facilitate the emergence of an online support community for individuals with fibromyalgia?*

*2) Why do individuals share their experiences of fibromyalgia on Instagram and what is the purpose of this practice?*

*3) What images do individuals with fibromyalgia select to represent their illness on Instagram and what meanings do they seek to convey in these images and the captions that accompany them?*

## **Methodology**

The study adopts an interpretive perspective whereby individuals construct the meaning of their illness in an emergent manner and in interactions with others (Creswell and Miller, 1997). The data comes from images posted on Instagram and their captions as well as interviews with twelve Instagram users through private messages. I used a mixed methods approach of content analysis, semiotics analysis and interviews to examine the meaning conveyed in the selection and nature of images displayed in posts. While these two methods are different, there are strong reasons to incorporate them both into a study (Leiss, Kline, and Jhally, 1997). Each has strengths that align well with this study. The content analysis allowed me to analyze a large amount of data, which is crucial when considering the number of images and posts on Instagram (up to 200 000 uploaded over a three day period), and determine the specific categories of different elements of the illness experience. The semiotic analysis gave me the opportunity to gain a more in-depth understanding of selected posts and the correspondence between the pictures and their captions. Finally, interviews provided an opportunity to triangulate the results derived from the posts and gain perspective from users posting about fibromyalgia. I also kept a detailed record of field notes which were used in part during the data analysis to work through the meaning derived from the dataset. This is further discussed in depth in chapter three.

## **Summary of Chapters**

This study is comprised of seven chapters in total. Following the introduction, chapter two reviews existing literature and research findings related to the research questions with a particular focus on the contested nature of fibromyalgia, illness identity, stigmatization, and the emerging role of online support communities for those living with chronic illness. Chapter three outlines the methodology and describe the data collected. Chapters four, five and six each present results of the thematic analysis. Specifically, chapter four explores how the meaning of fibromyalgia is produced on Instagram and the implications of this process. Chapter five is concerned with how Instagram facilitates the emergence of this online community and how individuals participate in the community. Chapter six discusses how the community sustains itself and why community members share their illness experiences on Instagram. Chapter seven concludes with a summary of the research findings, a discussion section recognizing some limitations of the study, and suggestions for future research. The appendix includes supplementary information such as the findings presented in table format as well as the interview questions.

## **Chapter 2: Literature Review**

This literature review begins by addressing the contested nature of fibromyalgia and the way this impacts individuals who are diagnosed. The second and third sections of the literature review focus on how the diagnosis factors into issues of identity and stigmatization. Diagnosed individuals can be stigmatized because symptoms of fibromyalgia such as fatigue or loss of energy can be equated with laziness or depression. In the last section, I review sociological literature that identifies several factors that motivate individuals with fibromyalgia to participate in online communities such as Instagram. Specifically, I discuss the need to study the role of online communities in validating the fibromyalgia experience and helping affected individuals resist stigmatization.

### **The Contested Nature of Fibromyalgia**

The cause(s) of fibromyalgia remain contested but “there is evidence for a genetic predisposition, abnormalities in the stress response system and possibly triggering events” (Fitzcharles et. al., 2013, p.646). The main symptoms of fibromyalgia include chronic pain, fatigue, stiffness and abnormal sleep patterns. Comorbid conditions include headaches, irritable bowel syndrome, anxiety, cognitive dysfunction and depression (Fitzcharles & Yunas, 2011, Sarzi-Puttini et al., 2012). Other symptoms include an exaggerated response to not only pain but also a variety of stimuli including hot and cold, odour and noise (Ceko, Bushnell, & Gracely, 2012; Arnold, Clauw, & McCarberg, 2011). Many of these symptoms are invisible, with no clear diagnostic markers, making the illness complicated to verify, thus leading to a diagnostic process that relies heavily on patients’ presentation of their symptoms. The range of individuals living

with fibromyalgia is often reported to be between 2-4% in North America, however, estimates suggested that as many as three in four patients with fibromyalgia remain undiagnosed (Wolfe, Ross, Anderson, Russel & Hebert, 1995; Branco et al., 2010).

Criteria for diagnosis has varied over the past decade. According to Fitzcharles et al. (2011), the original 1990 criteria for a diagnosis of fibromyalgia from the American College of Rheumatology was based upon the subjective experience of widespread pain alongside the examination of tender points. Tender points are designated areas within which a medical practitioner, usually a rheumatologist, as currently the syndrome is typically referred to a specialist, applies a specified amount of pressure to certain points on the individuals' body. As Chakrabarty and Zoorob (2007) write, "this amount of pressure does not produce significant tenderness or pain in patients without fibromyalgia" (p.250). However, the tender point method has been contested. Because of this, the 2010 ACR criteria for the diagnosis of fibromyalgia abandoned the tender point method and contained a method which was based on a symptom severity scale (Wolfe & Hauser, 2011). In 2013, Fitzcharles et al., published a paper based on the literature search used to develop the 2012 Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome. In it, they state clearly that, "the tender point count should not be used to confirm a diagnosis of fibromyalgia" (p.646). The tender point method is described as arbitrary as it does not address the symptoms most affecting patients as well as being a difficult test to perform (Wolfe, 2015). It is also stated that this diagnosis can be made in the primary care setting, rather than with a referral to a specialist and that it is not a diagnosis of exclusion and minimal testing (such as blood tests), is required. Although the tender point method has been debunked, many physicians may still use it as diagnostic criteria, making the standard for diagnostic criteria quite varied across the field. Due to this debate, many patients

wait for up to five years for an initial diagnosis (Arnold, Clauw, & McCarbeg, 2011). Further, because symptoms of fibromyalgia mimic other conditions, fibromyalgia is often a diagnosis of exclusion, meaning that other conditions must be ruled out first through multiple tests (Madden & Sim, 2006).

A recent white paper on the state of fibromyalgia in the field stated that data collected globally suggests that there is a lack of understanding of fibromyalgia and centralized pain. Findings suggest that there is an inadequate amount of education, training or experience in the field when diagnosing fibromyalgia (Arnold et al, 2016). For example, surveys found that;

[Among] Chinese rheumatologists, none of the 707 respondents had received any training on FM in medical school...80 percent of respondents reported having experience in diagnosing FM, 62 percent of whom had participated in continuing education programs on the disorder. Among those who had never made a diagnosis of FM, only 24 percent had received continuing education about FM, suggesting that lack of familiarity with FM may be associated with low diagnosis rates. In addition, nearly 80 percent of respondents acknowledged having difficulty in treating FM patients (Mu, Li & Zhu in Arnold et al., 2016).

Further,

In a survey...of primary care physicians, rheumatologists, neurologists, psychiatrists, and pain specialists in 6 European countries, Mexico, and South Korea, more than 50 percent of physicians reported difficult with diagnosing FM, fewer than 50 percent were aware of the American College of Rheumatology (ACR) 1990 classification criteria for FM, more than 50 percent reported they had inadequate training in FM, and more than 30 percent did not consider themselves to be knowledgeable about FM (Perrot et al. in Arnold et al., 2016).

These findings, as well as similar findings globally, raise concerns about the lack of validity or reliability of diagnostic criteria as well as treatment methods. Skepticism around the illness is fueled by these issues in the field, causing stigmatization (Arnold et al, 2016). The white paper also addressed issues around a lack of common terminology developed for discussing fibromyalgia as well as how little has been founded in terms of a professional organization for fibromyalgia which would allow for a higher amount of credibility, education, advocacy and changes to practice (Arnold et al., 2016).

Treatment of fibromyalgia is also debated in the literature but many researchers believe that a patient-centered multimodal approach is best (Chakrabarty & Zoorob, 2007; Fitzcharles et al., 2007, 2013; Gerwin, 2013). Most findings agree that exercise, cognitive behavioral techniques or educational therapy can be highly effective for those living with fibromyalgia (Chakrabarty et al., 2007, Fitzcharles et al., 2007, 2013; Soriano-Maldonado, 2015). As such, pharmacological and behavioural treatments may be simultaneously employed for treatment of fibromyalgia. Recent research suggests that the use of virtual reality integrated with activity management could be a beneficial tool for those living with fibromyalgia (Garcia-Palacios, et al., 2015). This type of treatment may allow individuals with chronic pain to risk performing certain movements or activities within the space of virtual reality, eliminating their fear of a painful body response. Findings of an initial study suggested that this treatment method has positive effects in reducing the impact of fibromyalgia on the life of the participants, highlighting a link between the benefits of incorporating technology with illness management (Garcia-Palacios, et al., 2015). Literature has also suggested the act of mindfulness may be beneficial to alleviate fibromyalgia symptoms (Jones et al., 2015).

A recent study identified how individuals with fibromyalgia self-report on their own symptoms and the cause of fibromyalgia flares (Vincent, Whipple, & Rhudy, 2016). When symptoms worsen or are exacerbated for a period of time, patients and clinicians often refer to this as a flare (Vincent et al., 2016). Participants identified various reasons for a flare such as stress, poor sleep, over exertion in nearly any aspect of their lives and weather changes. In order to deal with a 'flare', many participants explained that they had to refer to treatments that were known to work for them such as acetaminophen and ibuprofen as well as heat/cold and gentle

exercise. Participants also noted that in order to handle a flare they often had to rest, avoid everything, including social interactions, and wait it out (Vincent et al., 2016).

## **The Role of a Diagnosis**

The sociology of diagnosis is an important framework for understanding how a diagnosis is socially constructed, collaborative, and has political, cultural, and societal implications.

Brown, Tyson and Jenkins (2011) describe a social diagnosis as:

Social diagnosis is ‘social’ for two reasons: First it connects an illness or the act of diagnosis to a set of political, economic, cultural and social conditions or factors. Second, social diagnosis is conducted by different social actors, and the actions of one group of stakeholders often spill over to affect the actions of other actors (p 939).

The sociology of diagnosis takes into account the way different groups or stakeholders contribute to a diagnosis and broaden the perspective of public health to include those both individually and communally involved in the diagnosis (Brown et al., 2011; Jutel, 2015). Further, when an illness is contested, those involved in the process often seek to overturn beliefs and practices about health and medicine that are entrenched in “a network of institutions, including medicine, law, science, government, health charities/voluntaries, and the media” (Brown et al., 2011, p 940).

Fibromyalgia is a contested diagnosis. Various diagnostic criteria have been introduced over the past decade although there is currently no definite diagnostic test (Gerwin, 2013; Wolfe & Hauser, 2011). The contested nature of this diagnosis plays a major role in the way individuals construct their illness experience. Madden and Sim (2006) report that individuals with fibromyalgia can perceive their diagnosis negatively: “FMS appears to be an empty diagnosis; it conveys information, but little understanding” (p.2966). Because of this, many participants in their study struggled to make sense of their illness and secure the resources they needed for

coping with its symptoms. Further, because of the lack of knowledge about the etiology of fibromyalgia, affected individuals also constructed their own understanding of the condition, for example, by pinpointing the onset of their illness to an event in their life, like a car crash that occurred years earlier. For these reasons, the authors recommend that the diagnosis be used sparingly until the illness is better understood.

Yet, the diagnosis of fibromyalgia is reported in other studies to provide relief—it gives individuals a name to their pain and validates their illness experience. As Soderberg et al. (1999) report about one of their participants, “It was a good thing that the illness was named, because per the women, this means that the illness exists” (p 580). The diagnosis offered participants a type of validation—they were able to discuss their illness with their social group and justify why they were unable to maintain the same lifestyle they had prior to their illness. The diagnosis also validated their suffering as something which occurred in the body rather than the mind (Soderberg et al., 1999). Individuals with illness often accept an explanation from doctors due to their acknowledgment of a doctor being more knowledgeable rather than passively accepting biomedical superiority (Lillrank, 2003).

Women with fibromyalgia also struggle to be heard and understood in encounters with health care professionals. For example, Soderberg et al. (1999) found that women in their study often experienced a loss of credibility as a result of health care professionals not believing their complaints of pain and ill health. Most described a good encounter with a health care professional as “one in which the participants were trusted, listened to, and allowed time to tell their story” (pp. 580-81). They also felt lucky to be believed. Werner et al. (2004) found that women with fibromyalgia learned to present themselves in such a way as to avoid being seen as complainers. Skuladottir and Halldorsdottir (2008) found that the quality of the encounter with a

health care professional was critical to whether women felt empowered or disempowered in the management of their illness. They explain that “women in chronic pain, which often is unexplained and hard to handle, are vulnerable and require health professionals’ competence, caring, wisdom and connection” (p 898). In their study, women reported going as far as manipulating their appearance to ensure they came across as believable during the health care encounter. This involved changing the way they dressed and trying to balance between acting too strong or too weak. Participants “made their outward appearance harmonize with their internal experience of pain so their body would not be a traitor, by appearing from the outside much healthier” (p 898). Werner et al. (2004) similarly found that women constructed their appearance to influence how others perceived them and sought to avoid being viewed as complainers. The diagnosis however, can also be questioned by the one receiving it, based almost solely on the self’s recognition of their body and illness and whether the diagnosis or explanation given aligns with the self’s internalized knowledge of their illness (Madden and Sim, 2016).

### **Forming an Identity in Stigmatization**

As previously discussed, the diagnosis of fibromyalgia can be difficult to accept because of the lack of available information on illness management (Madden and Sim, 2006; Skuladottir et al., 2008). Many women who receive insufficient information about their diagnosis struggle to determine the extent to which the illness is impacting their life and question whether they are doing enough to manage their symptoms. Being unsure of this can cause individuals to feel guilty about being unable to cope with their illness, especially if they are missing work or other activities (Skuladottir et al., 2008). Crooks (2007) found that women living with fibromyalgia are

marginalized due to stigmatization, which makes adjusting to living with this illness even more challenging. The stigmatization of fibromyalgia stems from the fact that it is not fully understood medically and also because individuals with fibromyalgia often have to withdraw from activities they previously engaged in prior to the onset of illness (Asbring et al., 2002). These factors make it more likely for affected individuals to be accused of faking their illness. As Asbring et al. (2002) argue, stigmatization is a major burden on women living with chronic illness and that “to be accused of lying can be more of a burden than the illness itself” (p.157). Several studies report that fibromyalgia and its stigmatization are so disruptive to a woman’s identity that it can lead to the formation of a new identity (Asbring, 2001; Barker, 2002; Charmaz, 1995). As Soderberg et al. (1999) note, “Living with [fibromyalgia] means having a life greatly influenced by illness...the women appeared to be involved in a struggle, and life appeared to be heavy” (p. 578).

Asbring and Narvanen (2002) discuss multiple strategies to deal with stigmatization. These include; keeping distance from others, concealing, spending and/or withholding information and withdrawing from and/or approaching copatients (pp.155-156). They argue that stigmatization is a major burden on women dealing with chronic illness and that “to be accused of lying can be more of a burden than the illness itself” (Asbring et al., 2002, p.157). The strategy of spending or withholding information was prominent in the literature. Many women were careful about how they presented themselves and aspects of their illness and to whom. For example, as Hallberg and Carlsson (2000) write, “some women did not show signals of pain during the interview and said that they never showed their family and friends that they were in pain: they tried to hold the pain within themselves” (p.9). Some literature described how women had to conserve energy in order to attend certain social events or work, only to spend the rest of

their time needing to rest (Aspring et al., 2002 & Asbring, 2001). As Crooks, Chouinard and Wilton (2002) found in their study of women living with fibromyalgia, women embraced disability in certain places in their life, and did not allow it in others. This complicated process involved meaning-making related to disability and negotiating their realities to avoid any negative consequences that may be a result of revealing their illness. Recent research suggests that for women living with fibromyalgia, accepting that their work may be altered or ended due to their illness significantly impacted them, causing them to feel a great loss and shift of identity. Losing their abilities to work in the ways that they once had was a devastating loss and caused them to confront the challenges of a changing body (Juuso et al., 2016).

Small and large changes brought on by illness also impact the daily life of women living with fibromyalgia. A number of researchers have focused on how fibromyalgia impacts women's ability to perform activities they commonly did before the illness. For example, Crooks (2007) describes how women who no longer worked because of their illness experienced greater difficulty coming to terms with their altered abilities and made fewer trips outside the house. Asbring (2001) reports that women with fibromyalgia in their study experienced bodily changes that required them to change their schedule in order to conserve energy for certain events or daily activity like work. Charmaz (1995) discusses how the onset of chronic illness can change how a person perceives their body, "at best, the body is now a failed machine, an obstacle to be repaired, overcome or mastered. At worst, it has become a deadly enemy or oppressor" (p. 662). She also points out that the experience of chronic illness is unique in that those living with one must deal with bodily changes and physical incapacities that fluctuate and vary over time. Thus, affected individuals come to construct an understanding of their body that accounts for unpredictable symptoms and limitations that previously did not exist.

## Gender

Fibromyalgia mainly affects women, and the literature focuses mostly on women's experiences with the syndrome. Although a few studies include men (Charmaz, 1995 & Madden et al., 2006), they are limited in terms of the number of male participants and the vast majority are focused on women. However, one study done on 14 men living with fibromyalgia utilized intensive interviews with a narrative approach (Paulson, Danielson & Soderberg, 2002). There were a few key areas in men's experiences that were similar to studies on women, with some slight differences. Like women, men also struggled with forming identity after the onset of their illness. They described feeling that they were different men than they had been before. However, being at work caused them to feel different than others in their workplace and some felt they were no longer able to handle that same activity level. Being off of work or receiving disability seemed to provide relief, in that they no longer had to stress and were finally afforded "the freedom of not being put under pressure" (Paulson et al., 2002, p.245).

The authors also mentioned that similar to much of the research on women, men strove to continue normalcy in their daily lives and had a fear of "being looked on as 'whiners'" (Paulson et al., 2002, p.244). An interesting note here though, was that many men referred to role models like their fathers and grandfathers as individuals who had always worked through their pain and felt a need to be able to manage similar to those people. They would even mention individuals they had previously worked with, whom they perceived as being able to manage work while ill or injured. Another interesting point that the authors highlighted was the role of certain emotions as being central to the men's experiences. These included struggling to maintain the usual cheerful or happy manner that they felt others were used to seeing from them, and feeling more

emptiness or shyness. Sometimes, the illness meant that they could not perform previous tasks like at their workplace, which “made them feel like outsiders, which sometimes lead to suicidal thoughts” (Paulson et al., 2002, p.243). Further, an emotion that was not as prominent in literature on women living with fibromyalgia, was anger. Some of the men’s frustration or intolerable physical pain resulted in anger, usually directed towards their family.

## **Community and Online Support**

Communities of individuals with fibromyalgia can play an important role in the way newly diagnosed individuals reconstruct their identity and manage illness. As Barker (2002) notes, the self-help literature on fibromyalgia can provide a “practical, logical, and validating account of readers’ symptoms” (p. 293). With an illness that is so medically contested, resources such as self-help books can contribute to legitimizing the illness experience—they open up an avenue for individuals to learn from a community of others living with the same illness. Crooks et al. (2008) report that, “collective identification might facilitate a reinterpretation of disability as a shared experience and the basis for action, which may in turn encourage an embracing of the identity” (p. 1846).

However, in a society that has greatly developed in technology, there are further avenues for advice seeking or support communities to form. For example, one study found that 59 percent of European citizens used the Internet to look for health information in 2014 with between 82 and 87 percent looking for this information through search engines and 47 percent looking specifically at blogs and forums (European Commission, 2014). Research has also found that 41 percent of Canadians turn to the internet for medical advice, with 71 percent of them confidently

trusting this information (Glouberman, 2011). Medical institutions are including themselves in this phenomenon, with nearly 95 percent of US hospitals operating a Facebook page, and 50 percent with a Twitter account (Griffis, et al., 2014). Research has also suggested that within online support communities for individuals living with diabetes, those with the most experience with the illness tend to take on an expert role and are often referred to for advice (Chomutare et al., 2013). There has recently been a boom in mobile applications for chronic illness conditions like diabetes (Fernandez-Luque, Bau, 2015).

It is important to understand why individuals seek out these communities and where meaning-making about fibromyalgia takes place. One such community is online support groups. Barker (2008) studied an online support group website for users with fibromyalgia. This website allowed individuals to participate in a forum on multiple topics such as pain management or support for handling daily life with the illness. Barker (2008) found that “sufferers steadfastly framed their problems in strictly conventional biomedical terms” (p. 23) but also paradoxically challenged the competence of their doctors. As the author notes, “participants both recognize and bemoan the power that doctors have over them... [they] empower one another to persevere... but the only real power they have is the consumer power to search for a less reproachful provider” (p. 30). As such, these online support resources offer a space where participants can discuss their experiences of a poorly understood illness in ways that are not possible elsewhere.

Several studies of social media have examined how individuals use these platforms to seek validation. One quantitative study found that users are more likely to present a neurotic personality on Facebook to get the support they lack offline (Marshall, Lefringhausen and Ferenczi, 2015). These individuals created versions of themselves that could be validated through likes, comments and connections. Toma and Carlson (2015) found that undergraduate

students using Facebook selectively emphasized positive qualities and omitted the negative ones. However, students were careful to not change their self-image so drastically that they risked being perceived as liars. Gil-Orr et al. (2015) studied Israeli adults' Facebook use and found that the Facebook-self leaned towards a more socially acceptable version of the user's offline self adopting social norms that were likely to receive higher feedback via likes and comments. As they stated, "On average, users believe that their Facebook-self differs from who they really are and represents in part a person which adheres to social pressures, exaggerates positive facets, and downplays weaknesses" (Gil-Orr et al., 2015, p. 8).

Other studies have examined how individuals seek health advice on Facebook. In a qualitative study, Rasmussen-Pennington et al. (2013) researched the preferences of Canadian youth aged 12 to 18 in searching for information about mental health problems they encountered. Youth identified social media as their preferred source of information even though they recognized this information might not be the most trustworthy. Youth indicated feeling uncomfortable discussing mental health issues with a general practitioner and suggested that general practitioners were mainly interested in prescribing medications. Social media allowed youth to interact with people who had been through mental illness, whom they "considered to be reliable" (p. 192). A number of studies of Facebook support groups for HIV and diabetes found that messages pertaining to community or validating personal experiences were quite frequent (Gaysynsky, Romansky-Poulin, and Arpadi, 2015; Zhang, He, and Sang, 2013). This is a key finding given that research on these illnesses links social support to improved well-being (Gaysynsky et al., 2015). Limited research on the use of Instagram for health related communities identified that it is used for either educational purposes or motivation/support (Boulos, Giustini, and Wheeler, 2016).

Overall, research so far suggests that online communities and social media platforms play an important role in validating illness experience and offering support to those suffering from chronic illnesses, including illnesses which are stigmatized. This is a topic that requires further research in relation to people suffering from fibromyalgia.

## Chapter 3: Methodology

### Sampling and Data Collection

To begin collecting posts for my study, I had to create an Instagram account. After opening up an account, I included a description of myself in my profile and introduced myself as a researcher from the University of Victoria. I used purposive sampling to search for posts using the hashtag fibromyalgia (#fibromyalgia). The term *post* will be used in this study to describe the entire range of what individuals upload. This includes a username, image, caption (written statement underneath the image), likes, comments (likes and comments are posted by other users) and hashtags. Hashtags (#) are a function on the application that allows individuals to tag their photos with specific words that any other user can search (Instagram, 2016). Users have the option of allowing their posts to be public or private. Posts that are public appear on a stream when a specific hashtag is used. Once a user searches a word, a stream of posts from any possible location will appear in which anyone has tagged that word. The stream highlights the most recently posted images that used the hashtag, which typically will elicit up to 200 000 images from the past three to four days. I searched the word fibromyalgia in order to locate this stream of photos.

After I located the #fibromyalgia posts within Instagram, I then narrowed down specific users or images to analyze. Instagram recently introduced a feature on the application whereby at the top of the stream, nine of the most popular images with a specific hashtag appear before showing the entire feed (Instagram, 2016). The popularity of the images is calculated by the number of likes they receive. My first step was to look at these nine images in an attempt to

locate some of the most followed users who post about fibromyalgia, or which images have the highest number of likes that have posted about the illness. From this point, I navigated the app via comments, usernames, and hashtags to locate public users who have posted about fibromyalgia (utilizing the hashtag) multiple times. This was determined by viewing their page and images to find how many times they used the hashtag. The key here was to select the most popular images, via likes and viewing comments on these images. This relates to the hypothesis of this study, in that users are utilizing the app to form a type of illness community. By navigating this communication through the forms of interaction (likes, comments, hashtags), I gained access to individuals who partake in this community. After narrowing down individuals who post frequently about fibromyalgia, I selected fifteen popular individuals and from there, I analyzed three to four posts (that included #fibromyalgia) per user. The specific posts I selected met two criteria. One was that they must include the #fibromyalgia. The second was that the post had to have been up for at least a week but no longer than six months. The reason for this is that by the time a week has passed it is most likely that all followers or public users who will view the image have already done so it has probably reached its peak likes and comments or is at least relatively close to having done so. Having the criterion set to no longer than six months simply allowed me to ensure posts are relatively recent and limits the data set, as there was a large number of posts to choose from. This yielded 50 posts for the analysis.

## **Content Analysis**

I first used content analysis to systematically sort and analyze the selected Instagram posts. Because content analysis is a qualitative methodology with quantitative characteristics, it

worked well for analyzing this large amount of data. The goal of content analysis is to establish the frequency with which well-defined categories appear in the content under investigation (Ball and Smith, 1992). As Berelson (1971) explains, content analysis must be both systematic and quantitative. During and following data collection, I examined the posts to try to gain an understanding of the number and diversity of categories appearing in the content. In the analysis, I included the written caption that is underneath the image as well as aspects of the image. Once I began to see patterns, I developed four categories which were eventually titled: (1) The Day; (2) Pain and Management; (3) The Face of Fibromyalgia; and (4) Awareness. In content analysis, it is crucial that “any element of the content is coded under one and only one category and that the category system is sufficiently comprehensive to provide space for every relevant aspect of content” (Ball and Smith, 1992, p.28). In assessing the comprehensiveness of the four categories, I selected and analyzed 15 posts and examined the fit between their content and the categories. From this preliminary analysis, I concluded that the content of all posts could be readily assigned to the existing categories and that no further categories were needed. I felt that the four categories were sufficiently mutually exclusive and exhaustive to capture the content of the entire sample of posts. This process also allowed me to develop a standard definition for each of the four categories as well as criteria to guide the assignment of content. This maintained the systematic analysis of all posts and ensured that content was not assigned to more than one category.

Following this step, a procedure of numerical analysis was used to refine each category according to specific content Instagram users included in their posts in relation to the four categories. This coding was done on the basis of both meaning and frequency. For example, under the category of pain, several users posted about using pharmaceutical or alternate

treatment to relieve pain, while others commented positively on conquering pain. Many users also identified specific body parts as the site of pain, or included a caption explaining how they represented their pain in the digitally altered pictures they had uploaded. The results of this analysis are included in a series of frequency tables in *Appendix 5*.

Further, in the analysis of Instagram posts, I inventoried the username, image, caption, hashtags, the number of likes an image had received, and comments (which include other usernames). I also removed the username and gave posts an alphanumeric code instead to protect user anonymity and confidentiality. I created a metrics system to count the number of likes and comments each post received were counted in order to gauge which types of posts or themes were popular with other users.

Ten of the fifty posts were assigned to the category of *The Day* (20%), and the number of likes on these posts ranged from 6-213 while the number of comments from 0-43. The posts with the highest number of likes and comments tended to have the most detailed captions, which described exactly what factors had made up the good or bad day. *Pain and Management* consisted of nineteen posts (38% of the total data set) and the number of likes on posts in this category ranged from 4-331 while the number of comments from 0-42. Fifteen of the fifty posts were tallied under the category *The Face of Fibromyalgia*, making it 30% of the total data set. The number of likes on posts in this category ranged from 1-53 while the number of comments from 0-10. *Awareness* was smallest category with only six out of the fifty posts (12% of the total dataset). The number of likes on posts in this category ranged from 10-594 while the number of comments from 0-13, with some of the highest-liked posts falling into this category.

## Semiotic Analysis

Chandler (2002) states that semiotics involves analyzing signs or representations produced by humans to better understand the processes of meaning construction. A sign is the relation between two terms, the signifier and signified. The *signifier* can be in the form of a word, sound or image. The *signified* is the actual concept behind the sign (Danesi, 2004). On Instagram, the image is the *signifier* whereas the ideas conveyed by the image are the *signified*. For example, in this study the following image was analyzed using semiotics:



The image includes the following signifiers: the phrase “out of spoons” and the hashtag “#spoonielife.” The signified concept is the spoon theory. This image was posted around noon, which was also important for the analysis. Spoon theory was created by a woman living with chronic illness named Christine Miserando (2006). This theory is based on a metaphor for the fatigue of chronic illness, where a spoon represents a certain amount of energy. The idea is that a person with chronic illness starts the day with the same number of spoons as someone without chronic illness, but throughout the day, this person uses up more “spoons” or energy because of the illness. Therefore, individuals with chronic illness must be mindful of their spoons or energy levels before choosing what they tackle in their day. This post thus signifies an important aspect

of living with chronic illness by making reference to a popular theory circulating online. This particular individual indicated that halfway through their day, they were out of spoons or energy. This finding which offers insight into how Instagram users construct the meaning of the daily reality of living with fibromyalgia.

The creation of signs is always contextual and the context must be taken into account in semiotic analysis (Chandler, 2002). When conducting a semiotic approach, the researcher must take into account the denotation of the image as well as the connotation. The denotation is the initial meaning the image is meant to capture while the connotation is takes into account the secondary, or extended implied meaning (Anderson, Dewhurst & Ling, 2006). Further, a semiotic analysis takes into account intricate aspects of the post such as colours, positioning, and the hierarchal forms of meaning (Anderson et al., 2006). This more in-depth process complimented the content analysis and provided a fuller understanding of the types of meanings users ascribe online to their fibromyalgia experience. The focus was on the processes that helped to construct the meaning behind the image. An example of this may be working to understand how individuals construct a visualized representation of a largely invisible illness.

After the categories were solidified via the content analysis, I used a semiotic approach to gain a much deeper understanding of specific images, which was then followed by a round of interviews. The semiotic analysis was done on 12 posts. Due to time restraints it was not feasible to select more images as each required an in-depth and time-consuming examination. From posts in each of the four categories, two to four images were selected. In selecting the images I chose posts that were highly representative of their category, often these were posts that had the most number of likes or comments. This was premised by the assumption that these posts are most

likely to signify messages that individuals connect with, based on the high number of likes and comments.

In the process of analyzing the image, I examined how the image was constructed to communicate specific meanings. Anderson, Dewhirst and Ling (2006) refer to this as the denotation of the image. This step involves examining the manifest content, or the most tangible clear message being presented in the image. In order to accomplish this, it was necessary to describe the image, as well as connect the meaning between the caption and the image. By reading how an individual has described what is presented in the image, including what hashtags are chosen, it helped me form an idea of what this person was hoping to communicate to their audience. Further, the caption explains aspects of the image that are unclear, or the image may help to make sense of the written content. It was necessary to work to understand how the caption and the image work with one another to produce a desired meaning, as well as explain who the post is being created for. It was also important to consider the platform, Instagram, and how individuals use the functions in order to communicate. The functions include hashtags, size of photo as Instagram has recently introduced the option of different image sizes, and the opportunity to explain your post with a caption (Instagram, 2016). Further, during this part of the analysis, it was important to look at what is the main aspect of the image or what the individual most likely intended the main focus of the image to be. Examples of this are the individuals face, a specific body part, or a medication bottle.

In the next step, I analyzed the signified aspect of the post, or the more latent meaning. Here, I took into account the connotation, polysemic and referent parts of the post (Anderson et al., 2006). The connotation of the post refers to the implied meaning of the post and connotative chains can be identified in terms of how meaning is connected (Anderson et al., 2006). For

example, if the image was of a face that did not display illness whereas the caption mentioned pain, the clear meaning could be visualization of invisible pain but the connotation is the need for validation or legitimization as although the pain cannot be seen, it is still in existence. The polysemic aspect of a post is the consideration that meaning can work on a hierarchal basis, as within a single post, some meanings are more dominant or preferred whereas other meanings hold a secondary place (Anderson et al., 2006).

An example of this could be found in an image of a salad, with the hashtag fibromyalgia. While the user is clearly conveying that one moment of their day is involving eating a healthy meal, they may also at the same time be reinforcing that their daily reality involves maintaining a chronic illness which includes eating healthy foods indicated by use of the #fibromyalgia. Finally, the referent aspect explains what the actual sign stands for, which means analyzing the colour, repetitiveness, size, location, and positioning within the post (Anderson et al., 2006). This was one of the most important aspects in the analysis as Instagram allows an individual to edit their image before they post. In this editing process, individuals can add a filter on their photo which can change colour, brightness, contrasts, and fix blemishes on the photo (Instagram, 2016). Individuals are also able to crop the image and position it so that certain aspects of the image are centered or put to the side. Knowing this editing process helps determine which elements of the photo are privileged, therefore adding to the understanding of what the image is conveying. For example, a user posting an image that has the colour drained from it or that is presented in black and white may be using the lack of colour to symbolize a lack of energy. An important element here is identifying the types of cultural knowledge that that audience may already hold about this individual, chronic illness, or fibromyalgia, which is being referred to in the image (Anderson et al., 2006).

## Interviews

After completing the analysis of the images, I recruited and interviewed twelve Instagram users who were frequent posters with the hashtag of fibromyalgia in order to understand how their experience on Instagram corresponds to their daily lives and management of fibromyalgia. I initially set out to interview participants whose images I analyzed and who had popular posts, and thus most likely to be involved in the app community. However, while interest was high, keeping the connection was difficult due to participants not frequently checking their inbox or having symptom flare ups at time of data collection. I contacted a few other community members on the app and through continued communication, I ended up with twelve complete interviews.

I contacted users using a feature in Instagram which allows users to send direct messages to others. The message I sent described me as a Masters student doing research with the University of Victoria and asked if they would be interested in participating in the study. Once confirmed, I gave participants the option of conducting the interview through the private message section in Instagram or via email to provide convenience and confidentiality for the users. There is limited research on Instagram as an application in terms of collecting data within the app (see *Ethics* section below) but I received ethics approval from the University of Victoria Ethical Board and consent from interview participants. Screenshots were collected of the interviews held in the private message function. This allowed saving the data off the app and keep them confidential.

Once a user agreed to participate, through written form on the message thread, I sent them the interview questions. All participants received the same open-ended questions asking

them to describe the phenomenon in their own words (*see Appendix three*). The interview included questions about why they chose Instagram as a space to share their experiences with fibromyalgia and what and with whom they communicated with their images or ideas. Many of the questions centered on trying to gain an understanding of how a community is formed on the app, and if individuals used Instagram as a resource for their illness management. However, I also asked a specific question on the level of support individuals received to determine if these individuals faced stigmatization and/or receive support offline in their illness management. Questions on demographics were avoided to protect participant's anonymity. This also followed policy on the app which does not require participants to divulge this information on their profiles. It may have been beneficial to include geographical locations in this portion as health care systems vary by country, however, previous literature shows more similarities than differences of the lived experience of fibromyalgia cross-country (Arnold et al., 2016). The interviews allowed me to better understand the process by which individuals create posts and why individuals choose to share their illness experience in this manner.

Once I had the answers downloaded, I used thematic analysis to identify codes, themes and core categories. As Braun and Clarke (2006) describe, "a theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (p. 82). They further describe how the researcher can be flexible in determining which themes are most prominent or important based on prevalence but also meaning. I utilized an inductive approach with the interviews and did not assume the initial content analysis had captured all the participant's motivations or constructions of meaning. Once themes were identified, the data were read through again to ensure all the

themes were captured by the analysis. Three themes emerged from this data; (1) *Lifestyle Changes*, (2) *Support or Empathy?* and (3) *Awareness*.

## **Fieldnotes**

I chose to incorporate fieldnotes into my research as in essence I was immersing myself into the community I was studying and gradually developed an intuitive knowledge of the app and its users. I did not want to lose the insights I gained as I navigated the app and formed relationships with participants. Therefore, I took detailed notes throughout the process which aided the data analysis stage. Certain sections of my fieldnotes are incorporated into the discussion of my findings when relevant (*see chapter six*).

## **Incorporation of Findings**

Once I completed the data collection and analysis, I integrated findings from the content and semiotic analysis with interview findings and fieldnotes. The themes and categories developed from the different stages of data analysis complimented each other in that they shared similarities. By learning how interview participants described their engagement on Instagram, it was possible to gain further insight into the results from the content analysis. My findings are presented in Chapters 4, 5, and 6 as holistic accounts from all sources of data.

Fibromyalgia Instagram community members are referred to differently in this report. I refer to individuals I interviewed as *participants*. I refer to individuals involved in the Instagram fibromyalgia community as *community members* or a *singular member*. At points, I will use the

term *poster*, which refers to an individual who created and uploaded a post on Instagram. When I use the term *Instagram user* or *user*, I am speaking generically of anyone who utilize the platform, having no connection to the community studied.

## **Theoretical Foundation**

### *Goffman*

This study draws on Goffman's work on the presentation of self, role distance, and stigmatization. Goffman (1959) introduced the idea of front and back stages to account for how individuals interact in everyday life. In establishing a social identity, Goffman (1959) says that an individual portrays a "front" which is "that part of the individual's performance which regularly functions in a general and fixed fashion to define the situation for those who observe the performance" (p. 22). The front stage allows for others to understand the individual on the basis of projected character traits that have normative meanings. In this study, the front stage can be considered to be what individuals choose to share about their illness in both online and offline settings.

Goffman (1959) describes the back stage as such a place in which actors can disengage from their performance and where the audience is not able to view performers. Thus, on Instagram the back stage may consist of more intimate exchanges with people with whom the person with fibromyalgia interacts with in daily life (e.g., friends, family members, doctors). Goffman (1959) further explains how portraying a front can involve intensive interactions with others. He writes that:

Before the talk, talkers talk to their friends about what will and will not hold the audience, what will and will not give offense; after the talk, all talkers talk to their friends about the kind of hall they spoke in, the kind of audience they drew, and the kind of reception they obtained (p. 176).

The study also examines the issue of stigmatization. Goffman (1963) defines a stigma as “a special kind of relationship between attribute and stereotype” (p. 4). While Goffman discussed different forms of stigmas but not in relation to specific illnesses, there is a strong argument to be made for the role of stigma in the fibromyalgia experience. As the reviewed literature suggests, several stereotypes are associated with fibromyalgia (as the “attribute” in this context), including being viewed as ‘lazy’ or as ‘unwilling to get better’ (Asbring et al, 2001). Goffman further argues that stigmatized persons often cope with stigmatization by interacting with sympathetic others:

The first set of sympathetic others is of course those who share his stigma. Knowing from their own experience what it is like to have this particular stigma some of them provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person (Goffman, 1963, p.20).

Instagram thus can be seen as a platform where users reduce stigmatization by having their experiences with fibromyalgia validated by sympathetic others, some of whom also have the illness. Through this process, individuals are better able to cope with stigmatization, which is one of the heaviest burdens when living with fibromyalgia (Asbring, 2001; Barker, 2002). Drawing on Goffman’s concept of stigmatization, the study then aims to understand how individuals present themselves and their illness on Instagram so as to avoid or minimize negative reactions from others. The study will explore to what extent individuals are aware of their audience and construct their experience of fibromyalgia accordingly to convey a desired meaning. It will consider what illness experiences individuals privilege on Instagram and how these are expressed

in images and text. The focus will be on the decisions people make about what to display on Instagram and how this constitutes a form of resistance against stigmatization.

Goffman's work on roles and role distance are also considered in this study (Goffman, 1961). While many studies about online communication and interaction draw on Goffman's work (Sannicolas, 1997; Ross, 2007; Bullingham & Vasconcelos, 2013), few acknowledge Goffman's inclusion of technology and materiality in relation to his work on role distance (Pinch, 2010). Pinch (2010) argues that there is almost a hidden sociology of technology within Goffman's work that makes it even more adaptable to sociological studies of online interaction. For example, in his work on the situated role, Goffman describes role distance between children on a merry-go-round and the other children and parents surrounding them. Pinch (2010) argues that in this example, what is crucial to recognize is the technological system underscoring the interaction, i.e., the merry-go-round. Pinch (2010) explains that the staging of the child's role is configured by the machinery. The merry-go-round allows the child riders to sit in close-proximity to each other so they can monitor each other's behaviour and spins in such a way that parents are privy to view their child on a rotation. Therefore, the physical layout of the horses is critical for the social interaction to take place in the manner it does. Pinch (2010) therefore explains how this technology "plays a part in *staging* the role and is also crucial in terms of how the interaction is *mediated*" (p 414).

Pinch (2010) also points to Goffman's description of surgery, explaining how the interaction between a surgical team is highly dependent on the materiality and technology within the operating room. Finally, he highlights Goffman's (1959) work in the Shetland hotel where material elements, such as a door, become crucial in the mediation between front and back stage. This finding is apt for the present study where Instagram is home to multiple editing and

uploading options for users to mediate their communication and relationships. On this social media platform, it is necessary to upload an image to post which immediately mediates a form of communication not found on any other social media platform. Therefore, the materiality and technology of Instagram forces the interaction to be heavily reliant on the communication tools created.

Pinch (2010) recommends understanding Goffman's (1963) notion of co-presence, as not just bodily co-presence, but a co-presence that can be mediated through material, such as technology. Online gatherings, then, provide an opportunity for co-presence to exist in a unique way through time and space. On Instagram, this type of co-presence manifests through communication tools such as likes or comments on user's posts. Likes specifically give users a reminder of presence without overtly interrupting one's use of the app. Pinch (2010) argues that Goffman can be applied to online interaction in a very similar way that he could be applied to offline interaction "to examine technological choices specifically, and how they are negotiated as part of the interaction order" (p 423).

The present study addresses Pinch's (2010) interpretation of Goffman to online communication by examining technological choices and providing in-depth analysis of one specific platform that mediates online communication. The invisibility of technology or materiality or the taken for granted nature of technology is apparent with social media not by way of the actual physical technology (i.e. the mobile phone) but through incorporation of social media in the everyday reality. Those who use the Instagram space on an extremely frequent basis, which encapsulates most participants in the study, have become so well-versed on the space that the mediated forms of communication (photo editing, likes, hashtags) are taken for granted, or are in essence, invisible.

### *Online Community Theory*

Establishing theory to address studies on online communities is debated in the literature and many researchers have struggled with the fluid and flux nature of what a community is and how this transfers into the online realm. This is summed up well by Bruckman (2005); “much ink has been spilled trying to work out which online communities are communities” (*in Preece & Maloney-Kirchmar, 2005, p. 6*). The community in this study was deemed a community after recognizing the clear social ties and relationships that have formed, as well as the consistency of high communication within the group. Community in this study, is roughly defined as “[a network] of people tied together by solidarity, a shared identity and set of norms, that does not necessarily reside in a place” (Bradshaw, 2008, p 5). This evolved definition comes out of discussion around the idea of a *post-place* community, largely influenced by the virtual reality now accessible (Bradshaw, 2008). Initially, this study focused on the idea of a network that had developed within the broader Instagram community. However, upon investigation it became clear that the whole of Instagram is only communal in so far as that everyone on the platform is using Instagram. Beyond this, the platform is as public as our offline society is. Therefore, while networking forms the basis of communities on Instagram, community is actually developed through the basic characteristics Bradshaw (2008) describes; solidarity, a shared identity and set of norms. The solidarity within the members of this community derives from an understanding of their illness and the challenges that come along with fibromyalgia. The shared identity is that of an individual with fibromyalgia and a set of norms have been standardized within use of the platform and communication, which is described further in chapters four and five.

In a review of the literature on online community theory, Ren, Kraut and Kiesler (2007) detailed the use of common identity and bond theory when studying online communities. The

researchers specifically focused on how this theoretical stance could be incorporated into the design of online communities. Their findings aided in understanding how the present network studied on Instagram could be designated as a community. Ren et al. (2007) outlined the causes of common identity in communities which include; social categorization, interdependence, and intergroup comparisons. The key points of these factors is that a community identity can be created by a group of people belonging to the same social category, and interdependence means that the group has members that work interdependently on a common task or purpose. Intergroup comparisons describe the phenomenon of groups comparing themselves with other groups (Ren et al., 2007). These three aspects of common identity can all be related to the community studied here as the fibromyalgia community includes members belonging to the same social category of those living with the illness, the group works together to achieve goals (discussed in chapter 5) and the group consistently compares themselves with individuals who do not have their illness (discussed further in chapter 6). Therefore, this community achieves common identity.

In regards to common bonds, Ren et al (2007) recognize three main causes of bond attachment, which are; social interaction, personal information, and personal attraction through similarity. Social interaction is mentioned as the more frequent the interaction, the more likely individuals are going to develop stronger relationships within the community. Personal information relates to the idea of the more often there are opportunities for self-disclosure the closer interpersonal bonds can form. Further, with the sharing of such information, personal attraction develops between individuals in the community based on similar experiences. This bond attachment is also recognizable in the present study, as personal information is routinely shared between community members and the social interaction is extremely frequent between members, in both brief and lengthy written encounters. The researchers also identified that the

way in which communities accept, acknowledge and handle newcomers can have a major impact on the sustainability of the community. Other important elements essential in online community development include the prevalence of off-topic discussion, community size, core members and subgroups (Ren et al., 2007). Although Instagram was not built for the purpose of the fibromyalgia community to exist, the platform seems to afford the perfect space for this group to foster all of these factors. This study will address how these elements operated on Instagram throughout the findings discussion and through this, will highlight the way in which common identity and bond theory is practical for addressing this type of online community.

## **Ethical Considerations**

Ethical standards for internet research are varied and have been developing alongside research in the field. The Canadian Tri-Council Policy (2014) sets guidelines as to when Ethical Board Review is necessary in cases studying internet data. The guidelines suggest that ethics review is not required if the data are publicly available, even if it contains identifiable information and where there is no reasonable expectation of privacy. However, one must submit to an ethics board for review if the digital site allows participants to hold a reasonable expectation of privacy (Canadian Tri-Council Policy, 2014). Further, the UVIC Human Research Ethics Board guidelines state that informed consent is not normally required if observations:

- Do not allow for the identification of the participants;
- Do not involve staging or manipulating the setting/circumstances
- Are conducted in an open setting, and
- There is no reasonable expectation of privacy by those who are being observed (UVIC Human Research Ethics Board, 2013).

However, “if users of the site must create a login or represent themselves in a certain way...the privacy expectation of contributors to these sites is much higher” (UVIC Human Research Ethics Board, 2013, p.33). In keeping this in mind, it is important to examine Instagram and its platform to determine the level of privacy involved.

In order to engage on Instagram and view content posted on the app, a free account must be created and one must log into the app in order to use it. Instagram states that any content posted to their site is “non-confidential and non-proprietary and [Instagram] will not be liable for any use or disclosure of content” (Instagram, 2016). The explanation provided on the website makes it clear that while content technically belongs to the user, no confidentiality or protection is provided. Further, in its privacy section, Instagram explains that users have the option of who they share their content with. It states, “Any information or content that you voluntarily disclose for posting to the Service, such as User Content, becomes available to the public, as controlled by any applicable privacy settings that you set” (Instagram, 2016). The site then explains that users have the option to choose to set their content to private and have only approved followers see the content they post. However, if they choose to set their account to public, the content will be available to the public. By specifically choosing to use the term ‘public’, it appears as though while there is a logging-in process, Instagram makes the policy clear that anyone on the application is able to view your photo, eliminating much of the expectation a user would have to believe that their content is private. Further, there is no restriction as to who can join the free application, making it reasonable to consider it a public space, especially when considering that Instagram is home to upwards of 300 million users (Instagram, 2016).

Based on these studies, Instagram’s privacy policy, and the ethical codes, it seems reasonable that this study could be done without informing participants. However, because

Instagram has introduced the direct messaging feature, and because I interviewed participants, I contacted and obtained consent from interview participants. All participants were given a pseudonym and any identifying features were removed from the posts. Data were held on password protected files on an encrypted laptop that only I had access too. Further, precautionary steps to keep the data anonymous were taken and approval from the UVIC Ethics Board was obtained for the study.

## **Chapter 4: Online Embodiment: What this Community tells us about our Bodies Online**

The goal of this chapter is to describe the ways in which members visualized both fibromyalgia as an illness and as their physical selves on Instagram. This in essence is looking at how online embodiment plays a factor in this process. The chapter will first describe options presented on Instagram to construct an image, then will move to describing how the body was visualized on Instagram and discuss ways in which fibromyalgia was represented in posts.

### **The Instagram Platform**

An important element to choosing Instagram as the platform in this study was due to the processes afforded on the app to construct or edit an image. These processes factored in strongly into the semiotic analysis. For example, one of the key ways individuals can edit their images is by using filters. Filters are options selected before posting the image which changes the colouring, shadowing and lighting of the image. One may choose, for instance to make their image black and white, or give it muted tones. The Instagram platform offers 23 filters for editing with names such as “Moon,” “Lark,” and “Nashville” (Instagram, 2016). However, countless other apps exist that one could edit photos on before uploading. Further, in a different tab, users on Instagram can edit their photo beyond a filter. This includes an ability to brighten an image, raise the contrast levels of the image and sharpen aspects of the image. There are 13 of these types of options for editing. Users can also rotate or crop the image.

When uploading an image, users have the opportunity to either take a photo in the moment, or choose from the library of photos on the phone taken previously. Once uploaded, the

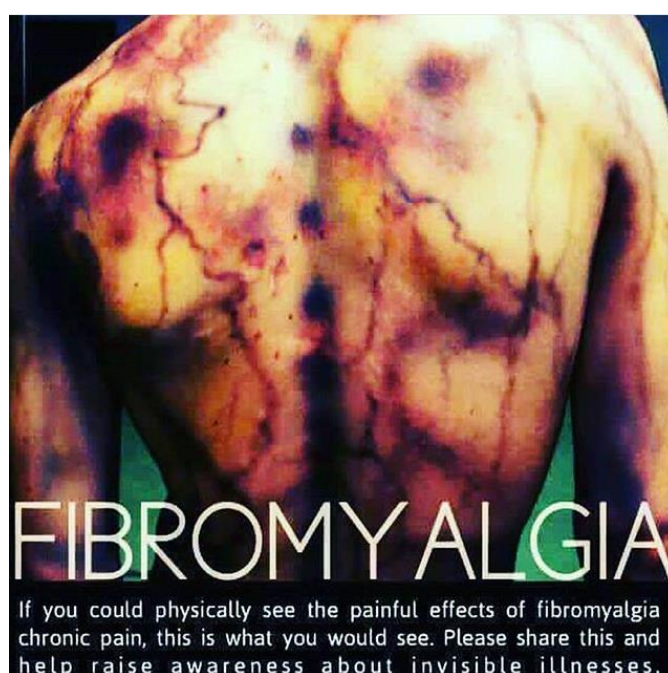
editing process takes place, where users can change the image with the previously discussed tools to the extent that they wish to, or make no changes at all. Following this step users have the ability to write a caption about the image and choose if they would like to instantly share the post on other social media accounts at the moment of posting or tag other users in that post. After this, the user hits the “share” button and the post appears on the feeds of their followers as well as on their profile page. Considerations of the entirety of this process were important during the semiotic analysis and gives context to the abilities of the Instagram platform.

## **Re-Visualising the Body through Imagery**

One of the key foundations of this study is that the focus is on an illness known as *invisible* as fibromyalgia produces very few, if any, outward symptoms. One of the reasons fibromyalgia was the illness chosen to study on Instagram is due to this factor as well as the idea that the illness is difficult to understand, diagnose, and sometimes even treat. Instagram is a platform that requires the user to upload a visual component, a photograph or computer generated image in order to post. This means that if a participant is trying to convey meaning about fibromyalgia, they must somehow visualize what is often invisible to others. A strong focus both in the posts and interview data was the idea of describing the body or symptoms, and a creation of re-visibility for the body. Once a participant chooses to upload an image, they have nearly endless possibilities online to choose how they will represent their body or the illness that has inhabited it. Sometimes this was done with a clear shot of an actual body part in a photo and often the participant had edited the photo with a filter available on Instagram in order to enhance certain aspects, which will be discussed further. Other images were computer-generated, meaning that users could build an image online, choosing the focus of the image, the colours,

and the words that may be placed on the image. Participants could also use images that they had found online in order to convey a certain meaning. This was made clear when beginning the data collection phase, as some images were posted by multiple users.

This finding is important as it shows how participants were able to transpose the physical self online. One of the most jarring and powerful computer generated images is inserted below (*Image 2.1*). This picture features a badly bruised body with writing under the picture explaining that if fibromyalgia was visible, this is how it would look:



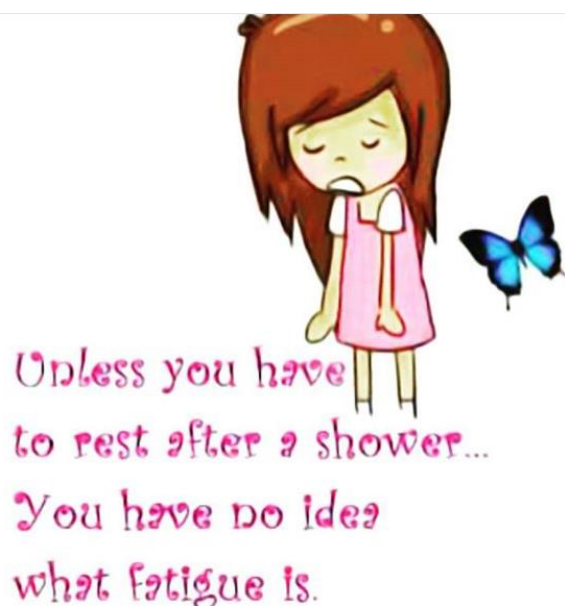
*Image 3.1*

Underneath the image is written:

If you could physically see the painful effects of fibromyalgia chronic pain, this is what you would see. Please share this and help raise awareness about invisible illness.

This image directly addresses the phenomenon of visualizing the invisible. It also speaks to building the body online. A participant is showing their audience that this is what they *could* look like, if fibromyalgia manifested differently. Another picture featured a young cartoon character girl against a white background standing with her head tilted down and a sad look on

her face with a caption stating, “Unless you have to rest after having a shower, you have no idea what fatigue is.” This is pictured below (*Image 3.2*).



*Image 3.2*

While the focus in this image is less about the actual body and more on the writing, the body presented in this image is female, hunched over, with a pale complexion, a frown upon her face and a generally sad expression. The body here not only represents fatigue, but an overall sad demeanor, giving the impression that an illness being visualized as fibromyalgia related to being tired, forlorn, and maybe even gloomy. In contrast to the pink dress on the girl's body and the pink writing, there is a blue and purple butterfly positioned beside her. The significance of the butterfly is that butterflies are often associated with fibromyalgia, a phenomenon known as the *butterfly effect*. The butterfly effect has its origin in chaos theory, in which it is described that small changes in initial conditions, such as a butterfly flapping its wings can cause drastic changes in results, like a hurricane across the world which would not have occurred without the flap of the wing (Bernhoft, 2012). The unpredictability underlined in this theory aligns well with the nature of fibromyalgia. In fibromyalgia literature, the butterfly is symbolically important for

a few reasons. One is that a butterfly appears light and almost weightless. This lightness is meant to represent the ease of touch or sensory overload that can impact someone with fibromyalgia. Often those living with the illness will say that even a hug or light touch on their body can create pain. Therefore, the lightness of the butterfly represents this sensitivity of fibromyalgia sufferers which can affect not just touch, but other senses as well. The butterfly also represents the metamorphosis that occurs when someone is diagnosed or when the illness onsets. Just as caterpillars' form into butterflies, those with fibromyalgia must shed layers of their identity and transform their own bodies into ones that live with an illness (Tyler, 2012). In this image the contrast of a bright blue, almost lively looking butterfly beside to the small, hunched over body provides a unique contrast. Without knowing the symbolism of the butterfly, the image can highlight just how fatigued the body is in comparison to the bright liveliness of the butterfly beside it. However, once one is aware of the symbolism of the butterfly, using the butterfly in the image furthers the meaning of the body being weak, sensitive and fragile. These layers of meaning are constructed on each Instagram photo, which helps to explain the in-group and out-group phenomenon of the community. Friends and family may see this image and understand the main point, whereas those familiar with illness and awareness movements around fibromyalgia may recognize the deeper meaning of including a butterfly.

Images of body parts that were taken by participants usually had captions describing the pain that was being experienced in that specific area of the body. For example, one participant posted a picture of their legs on a sandy beach in the sun with water in the distance. The caption read, "Fibromyalgia legs are tired!" Another post showed an individual's hand with a compression glove on it. The caption underneath stated, "My hands are so swollen! And painful. My fingers look like sausages. A nap is needed." Other images similar to this highlighted a

treatment method beside or with the part of the body in pain. For example, one individual posted a hot water bottle on top of their aching legs. Others showed pictures of their pill bottles for medications that were needed to manage their pain symptoms. Most comments on the images taken by individuals typically revolved around support. A number of individuals made treatment and pain management suggestions but usually alongside words of encouragement. For example, on most posts, other members would comment that they understood what the poster was going through or sent the original poster love and support. This aspect of the theme also highlighted the community among this group as it showed some form of friendship and caring among users.

## **Sharing the Pain**

Interview data did not tend to show that participants were trying to reconstruct their bodies online, but when asked what they chose to post about with the hashtag *#fibromyalgia*, some hinted at this process;

I like to post about how I actually feel like with my pain and symptoms because I don't think I really show that often. Like my joints might be really hurting but if I don't tell anyone that then they don't know. So sometimes I post about it instead and take a picture of my wrist or something.

I post all kinds of things...when I am feeling sick or in bed I like to post to show people that I can't always be at work or on my time off this is what I have to do most of the time. It is nice to know other people are doing that as well and feel the same type of pain.

Although these participants do not directly say that their goal was to actually manifest their physical body online, they describe the process of wanting to showcase their physicality through the images. They discuss a desire to have others recognize their physical symptoms in a way that they feel they cannot do offline. One may argue this and say that you could show another person your wrist and explain that the pain is there. However, the advantage of posting this online

relates to the context functions in your exclamation of pain in your wrist. Online, participants have the option of posting the image and caption simultaneously, therefore the presentation comes instantly across as one entity. Offline, others may see your wrist all day long, but in order to get someone's attention you need to actually verbalize where the pain is. This is likely to follow by a reading of the other's body language and verbal response, which as discussed can lead to stigmatization if the individual with pain does not receive a desired response. By posting instead about the painful wrist, the post can convey the exact meaning the participant is trying to communicate to others and they can articulate the post in a way that may help secure the response they desire. Once a post is made, a participant can still backtrack and edit the caption if they wish or even erase the post, essentially deleting it from their history. Therefore, the participant may feel they have more control over their claim of pain than they do in the offline world. You cannot take back or edit the words you verbalize to someone. While this may not appear as a major benefit, often individuals living with chronic illness struggle with who they wish to allow to know about their illness or to share information with. Therefore, this way of claiming illness allows for take-back when necessary.

While the possibility of deletion is an advantage to posting online, there is also an advantage in the permanency of the post. If participants have posted about their painful wrist six weeks ago and are having the symptom again, they have created a type of marker for themselves to look back on. This is beneficial to keeping a record of symptoms but can also aid the individual in sharing their narrative. Anyone new to their page can automatically see this post and gain instant insight into their condition and how their body operates. This type of record is nearly impossible to create offline. An individual a participant meets offline cannot learn from them on their first meeting that the participant suffers from a painful wrist, or that the touch or

pressure of a hug could send their entire body into pain. It is often likely that a new person would not know about someone's symptoms until they developed a closer relationship. However, having posts created with lengthy explanations skips these possibly uncomfortable, awkward encounters and allows a participant to say this is my illness and this is how it affects my daily life. While this may not be the main intent behind posting, it creates a completely new dynamic to social relations. Individuals new to your life are able to see a selective, edited biography before even speaking with you. While the motivation behind this varies, regardless, it creates a unique social space for members that may not be possible elsewhere.

## **Selfies**

An interesting finding linked to the posting of body parts was the consistent attention on posts of the face. This finding featured images of individuals' faces, or "selfies." Selfies are a popular social media trend that pop up on almost every platform and are relatively popular on Instagram. These selfies appeared to be uploaded either to share a specific moment in one's day or to express ideas about the sudden onset of illness symptoms. While the selfies would be too identifiable to include in this report, they encompassed many different facial expressions. Captions accompanying selfies included comments such as, "Pain! There is only so much a person can take before it starts to wear them down," "I feel unwell," and, "Putting on a brave face but everything hurts so much." Nine of the fifteen selfie posts collected were of an individual with a frowning face and/or crying, to highlight their current suffering.

Two of the selfie posts were of individuals smiling and one face seemed to convey strength with light shining onto her face. This was done with a stoic facial expression with the

individual's eyes looking straight into the camera. These images appeared to convey the ability to keep a positive attitude while struggling with a chronic illness. While these individuals were not necessarily seeking to be an inspiration to others, many comments on these pictures included phrases such as: "You're amazing!" or "It is so great to see someone living with this illness and still smiling!" In the caption, the posters acknowledged that they were smiling despite the pain, and this sense of positivity appeared to be reassuring to other community members living with fibromyalgia.

Selfie posts usually included a caption that situated the post in a specific time and place. This means that it appeared as though the selfie was an attempt at encapsulating exactly what the user was going through in that moment. Selfie captions often included a feeling of frustration of some type. For example, one post described a change in career path by a user known by the pseudonym Jessica;

Pain! There is only so much a person can take before it starts to wear them down. I am tired of getting the run around. I received my #fibromyalgia diagnosis in 2010 and my #thoracicoutletsyndrome diagnosis in 2015. I have lost my career path as a Personal Trainer and more and more I feel like I am losing myself. I will never get too far gone. I have my sweet loves to be strong for! Lord knows I could use some relief.

The facial expression that Jessica posed in this selfie was one of frustration, with pursed lips to the side and little expression in her eyes. She was sitting on a couch with her hair done, and a knitted sweater on. The couch had a blanket on the back draped over it. The impression the image gave off was not that she had been lying on the couch but may have sat down for a longer period of time to rest, based on the positionality of the woman in the image. The caption on the post indicates that she has children ("my sweet loves"), and combining this explanation with the image would allow someone viewing the post to see her as a busy mother who was forced to take a break from her day to sit down and rest. The colouring in this image was typical of the category. While Jessica was wearing black and the couch and blankets had fairly neutral

colours, the image did appear as though an Instagram filter had been used. Most selfies posted utilized muted or grey-based tones, probably created via the apps filters. This emphasized a drained or tired look amongst all images, possibly added by the user to depict the mood in that moment. Many of the images centered the face within blankets or bedding, draining the skin even more amongst the colour of the blankets. Individuals often had their eyes averted away from the camera, which allowed the face to look more vulnerable, or sad. One image hid a woman's face under blankets, only showing her forehead and hair on the pillow. The caption stated that she was sick of waking up in pain every day and was planning to just stay in bed for the day.

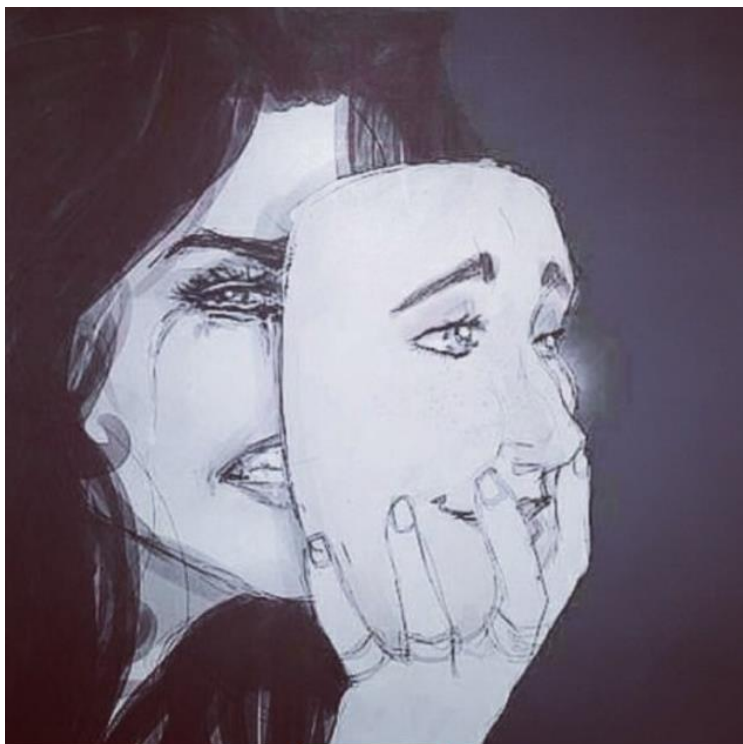
The more positive posts were an exception to this, with bolder, brighter tones being utilized and faces usually looking directly at the camera. For example, one user, whom I will give the pseudonym Grace, posted a picture of herself with a stoic look facing the camera with the light of a window shining on her. The caption stated;

Everyday holds great potential. ASK, RECEIVE, BELIEVE. Living strong & Living well – despite my Fibro- it does not define me!

Grace was wearing a bright blue shirt with long red hair. These colours in the photo stood out significantly, likely emphasized by a filter which brightens the image. These filters change the potential meaning of the post by setting a tone to match what mood the user is hoping to convey. Comments on selfies followed the initial tone set by the user and offered words of encouragement on the posts that signified frustration with comments on the more positive posts, like Graces', tended to be proud and happy for the user posting.

One image which stood out as unique to me is the one pictured below (*Image 3.1*). While the image was not of an actual living self, it was computer generated; it was categorized as a selfie as it did picture a face and appeared to encapsulate the emotions that other selfies

attempted to do. The image shows a crying woman's face, slightly pulling away her mask which is of a smiling face. The muted black and white tones allow for a more darkened, grim tone to come across.



*Image 3.3*

The caption under this photo stated:

Having a really tough time. Pain has been so bad and I am barely sleeping because of it. I tried to explain to a colleague about it all and she said “I guess we just have to live with these things.” People just don’t understand and appreciate how hard getting through each is with a debilitating chronic illness. But as usual, I kept my brave public face on as I will do all day at work tomorrow. I thought this would get easier but it just gets worse.

This post highlighted the act of those with fibromyalgia having to hold a “public” face which clearly portrays a different emotion than the one they are feeling. In this case, it felt like the participant was wearing a mask. This specific aspect of the post is unique as it suggests Instagram is a space where the participant can be honest with those viewing the post and show the true pain that the participant was experiencing. As discussed, with the colleague, or public, it

often became necessary to hide the pain the individual was feeling as others would not understand or appreciate what it took for them to simply get through their day. Further, individuals may simply not be able to tell everyone that they encounter about what was going on underneath their skin. By putting on the mask, one is able to participate in daily activities, but their true pain or emotions are hidden. In this case, the individual posting felt comfortable enough on Instagram to showcase those typically hidden feelings. Comments on the post spoke to this feeling being a common theme for others living with chronic illness.

Selfies are not an uncommon trend on social media, and are posted by all users, not just those with chronic illness. However, there appears to be another level of motivation when selfies are purposely tagged with a hashtag that identifies the individual as living with illness and being affected by symptoms. With an invisible illness that is coupled with stigmatization, posting one's face with the hashtag *#fibromyalgia*, typically alongside a caption that describes a specific aspect of illness experience, an individual may not only be able to explain what their physical body is experiencing but may also be able to defuse such stigma by letting strangers as well as friends and family know who fibromyalgia affects. These posts could be counteracting the stereotypes of fibromyalgia in public discourse by narrating a lived experience in an intimate way.

## **Representation of Illness**

Many participants framed their experience in relation to their day. Participants often connected how they felt physically to the weather or amount of activities they had to achieve that day. In her extensive work on chronic illness, Charmaz (1997) describes how individuals with chronic illness often frame their experience in terms of having good days and bad days and of living day by day as a strategy for managing illness symptoms. This aspect of living with chronic

illness is also present on Instagram. Many participants included captions with images they uploaded that alluded to whether the day had been good or bad and identified factors that contributed to their sense of health and well-being that day. Some mentioned needing to conserve their energy for future activities or that they had pushed themselves too hard the previous day and were now experiencing a flare up of their symptoms. They typically described a fibromyalgia flare as lasting anywhere from a day to multiple months during which time symptoms caused them to experience several “bad” days in a row. Members uploaded posts on specific aspects of a bad day or to recap an overall bad day with a caption. This allowed them to share their experiences of a bad day beyond the time and space in which it occurred. In this way, those who may be confined to bed were still able to express themselves and communicate with others about their illness experience.

Participants identified a variety of factors that contributed to a bad day. Physical symptoms were always at the forefront of a bad day, but so were external factors such as bad weather (cold, rain, snow or too much heat), negative doctor experiences, or illness-related stress resulting from having to fill-out disability or medication claim forms, for example. Four posts discussed bad days in relation to having to make a decision to drop out of or cut back on work or schooling due to illness. While physical symptoms often characterized a bad day, posting about bad days also centred on the extra activities that were needed to manage a chronic illness. This included, for example, a doctor not appearing to be supportive or a long wait time to see a specialist. Participants tended to frame their experience of illness in terms of the additional work needed to live with fibromyalgia on a day-to-day basis. This is important to note as adapting to life with a chronic illness can often increase the amount of stress or work an individual has to

handle due to the tasks required to manage a chronic illness. The posts on this phenomenon highlighted the importance of this in user's daily realities.

Seven posts included a caption underneath the image requesting support and/or advice, e.g., "Is anyone else experiencing this bad weather in their body?" or "Do the bad pain days ever end?" By seeking out likes or comments with such captions, members sought comfort and validation of their experiences of a bad day. The frequency of such posts also suggests that individuals may be doing so because they are feeling isolated and perhaps lacking offline support. Posting about a good day with fibromyalgia was often done in relation to managing a bad day. The most unique part of this finding, however, was that images typically posted about one's day did not depict a body part, or face. They most often depicted some type of physical setting. Many of these posts were of weather, the sky, areas of a home, or a bed. The representation of how a user felt was often highlighted in the imagery chosen, giving more context to how fibromyalgia felt, and showing how intimately the internal illness is linked to external factors.

Three of the posts depicted bad weather. One post included an image of a dark, stormy sky with a small ray of sunshine peeking through the clouds, shown below (*Image 3.4*).



*Image 3.4*

The caption underneath read:

Do you see the light? Always remember the storm will end and you'll see the sun again. Yesterday was 'stormy' for me. Pain was high and there were no answers. Today I can see the sun between the clouds. I still have pain, but it is a lot more bearable than yesterday. They will get specific tests done today and hopefully have diagnosis tomorrow.

This post frames challenging times in terms of how a good day might follow a bad day. The poster is also encouraging others to focus on the light that follows their dark time. The theme of weather and health was found in both the image and caption. Images of rain, snow, or a gloomy sky were continuously used to illustrate a bad day whereas sunshine or light reminded participants of positivity, inspiration, and a marker of a good day. The impact of weather on the illness experience was highlighted both in terms of physical health and symptoms as well as mental health and mood. Rain was associated to cold weather in that it caused physical symptoms, like arthritis, to flare up and highlighted a dreary feeling that reflected the participant's mood. This finding highlights how individuals living with fibromyalgia linked their symptom experience with the weather.

Other times, participants highlighted a good day by listing what they managed to accomplish despite fibromyalgia symptoms. These posts often included descriptions of spending time with family or friends. For example, one post highlighted how a bad day turned into a good day when the participant was able to make it to a beach to see the sunset after a day of fatigue and a negative experience with a doctor's appointment. Another post showed a participant's legs up at the movie theatre, with a caption describing how it was worth risking a bad day tomorrow to have a good day at the theatre today.

The post that fell into this category that had both the highest number of likes and comments was one of a snowy road, pictured below (*Image 3.5*). The post gained 213 likes and

42 comments, not including the original user's replies to the comments. The hashtags that the initial user, whom I will give the pseudonym Zoe, used in the caption included; spoonie, chronicillness, chronicpain, fibromyalgia, arthritis, invisibleillness, blizzard2016 and heartbroken. The caption described how during this day of a blizzard Zoe received a phone call that her disability insurance claim had been cancelled as a pre-existing health condition was being blamed for her currently missing work. She then wrote that she felt broken.



*Image 3.5*

Underneath the image multiple comments centered on encouraging Zoe and giving her support for her experience. Here are some examples of the types of comments;

Oh my gosh. My worst fear is that one day my disability will call and end my coverage before I'm well enough to work. So sorry to hear you're going through this.

I am so sorry to hear that. When you struggle with health it seems impossible to worry about money on top of that! Really hope you get the help you need.

We've been fighting my insurance for the last few months. They don't want to pay for my extremely needed iv infusions anymore. Scary.

\*hugs\* Ugh. I laugh when people tell me to check into disability for fibromyalgia...no one cares. I can't even get doctors to understand after being diagnosed. Never mind government. Gets me upset.

Zoe posted many replies to the multiple comments she received, one stating;

It sucks you all understand this situation bc [because] we all go through it. Ugh. Thank you so much for your kind messages and support. I'm so thankful for you guys!

Another one of her replies discussed the health care context in Canada;

We just got a new prime minister here who is liberal so it should be much better than before (hopefully!). It is so frustrating having these illnesses. I'd much rather be at work. Thanks so much for your sweet words and support! Sending love right back!

This thread of comments transforms the meaning from Zoe's initial post in complex ways. While many comments showed support specifically for Zoe, the ones discussed here go a bit further in their communication with the initial post. First, other users tend to mainly connect to the caption and not the image. For example, no one commented comparing the weather in their area to the weather in the image. Others relate Zoe's situation to their own and it appears to strike a chord of fear in relation to their realities. This highlights a fear that individuals with chronic illness may live with in which those without chronic illness would not. As one user describes their experience with fibromyalgia in that it is not widely understood by people, doctors or government. The connection to government is also interesting to watch as the post develops through comments. When Zoe states that "we just got a new prime minister here who is liberal" the connection is being made to Justin Trudeau and his recent win in Canada. This is important in that a change in politics is connected to the individual experience of illness and helps to provide some hope to a situation related to disability insurance. The post develops in meaning by Zoe providing more context throughout the comments section as well as gaining responses that explain why discussion around disability insurance can evoke fear and concern for other's

situations. Zoe is a community member who appears to be very embedded in the community with over 5000 followers and a consistent stream of posts related to her illness.

Another Instagram user, whom I will give the pseudonym Dan, described having three good days in a row, and linked this third day to time spent with family. A part of the caption on the post states;

Feeling free today – Day 3 of good days & I've come to visit my amazing grandparents. Although they don't understand my illness & the way it has made me feel, they have been there for me every step of the way.

The image of the post connotes more of a feeling than of the actual lived experience as described. The image is shown below (*Image 3.6*).



*Image 3.6*

To analyze this image as an isolated fragment, the armchair suggests a comfortable, worn feeling with the pink hue and light in the corner standing out in an otherwise dimly lit room. The way the pillow is structured in the chair gives off a feeling that someone was just recently sitting. Framed pictures in the background of the image make it clear the home is lived-in and has a family. Without given the context of the caption, one may assume this is a family home or even

suggest a grandparent's home due to the slightly dated furnishings. After reading the caption, it becomes clear that this is a comfortable environment for Dan and possibly a place where he can speak freely about his illness. Included in this post were 25 hashtags, some of which were; groundhogday, fighting, endlesspain, chronicfamily, butyoudontlooksick, onedayatatime. The post gained 60 likes and had 6 comments that lacked a cohesive discussion with Dan not replying to any comments. This type of post suggests that some posts do contribute to the discussion of fibromyalgia on Instagram but may stand alone. By stand alone, I mean that in opposition to Zoe's post (*Image 3.5*), Dan was not in need of a discussion to follow on this good day. He shared his comfort zone, described his good day, and was not necessarily looking for support or advice. However, like Zoe's post, those commenting back could relate to the way Dan was feeling. For example, one user commented:

Seeing people you love gives you such an emotional boost, doesn't it? I missed out on a visit to see my much loved grandma and a then a day out with my friends so I was feeling pretty low...

This individual may or may not be someone that Dan knows offline and may not be someone with illness but very possibly is due to them missing out on opportunities to visit family. These types of posts and comments help to provide some details on what types of support can boost individuals living with fibromyalgia and how this support may make a difference in life with the illness, contributing to more "good" days.

Posts that described a day were unique in that they did not represent one single moment locked in time and space but rather, a collection of moments that made up an overall positive or negative experience. A day appeared to be the unit of time within which an individual categorized their illness experience. Captions made reference to symptoms, support, work, school, or appointments, which all contributed to turning the day into a good or bad experience. Comments on these kinds of posts often included statements such as "hope tomorrow is better,"

“had a similar day today myself”, and “stay strong.” This supportive feedback individuals received from these posts may be a factor in explaining why individuals chose to post revealing details about their physical and emotional experiences on any given day. Further, it helps to clarify that living with fibromyalgia is an all-encompassing experience that impacts all areas of one’s life.

## **Chapter 5: The Instagram Fibromyalgia Community: How did it form?**

One of the most important goals of this research was to identify how this community formed, how it is maintained and if this community is sustainable in the way that it is built. This chapter will describe the way in which the community was formed utilizing platform tools such as hashtags, likes, comments and follows. It will delve further into the motivation for forming the community in terms of the creation of a social space and it will end by explaining two of the main goals for forming the community; defining fibromyalgia and bringing awareness to the illness.

### **Connecting on Instagram**

#### *Hashtags*

Hashtags (#) form the basis for connections in this community. In order to initially access the community, hashtags are the search functions that allow a user to find and locate others posting about fibromyalgia. This is the way I identified the community, searched for posts, and maintained connections with users on many occasions. By hashtagging a post, an Instagram user opens it up to be searched. This is important because it makes a post identifiable. If a user wants others to see their post about fibromyalgia, they can include a hashtag in their caption that will allow it to be searched and this will likely guarantee that a wider audience than just their followers will view it. While not all members in the community may use the hashtag, they at least know that they can search it. Not all posts that a member uploads may include the hashtag,

some may not. For example, with participants in the interview portion of this study, three put the hashtag on only some of their posts and the other nine used the hashtag (#fibromyalgia) on all of their posts. The amount of posting done by interview participants was varied. Six participants posted every day, three posted about three times a week, two posted a few times a month and only one posted not often, about once every two months.

Hashtags are incorporated into the caption portion of the posts, and can be included in two different ways. One way hashtags are used is at the bottom of a caption typically in a group. This is highlighted below (*see Image 1.1*). This format is likely to achieve more views, as more hashtags would yield a higher possibility of people viewing your post as any of the words searched would include your post.

 Taking a restorative Saturday by the river. How are you recharging this weekend?  
 •  
 •  
 #fall #restore #calm #health #wellness  
 #healthy #restorative #freshstart #stress  
 #breathe #chronicimmunedysfunction  
 #chronicID #chronicillness #chronicdisease  
 #chronicpain #cope #pain #strength  
 #autoimmune #spoonie #spoonielife  
 #invisibleillness #lymedisease #fibromyalgia  
 #lyme #asheville #river

*Image 1.1*

Another more nuanced way to include hashtags is as part of the caption, featured below (*see Image 1.2*). While this may not yield as many views, it may instead feature key words acting as important links to the community. Further, the caption may present a more narrative feel, with an incorporation of the search function included. Of these two methods, the first approach was the one most often taken.

[REDACTED] Had a 17 day  
 #fibromyalgia #headache so decided to take  
 it somewhere nice. The #sculpture #park in  
 #farnham. First shot of many - a stack of  
 #glass  
 #weekend #walk

*Image 1.2*

### *Likes*

Likes are included on posts by either double tapping on the image portion, or tapping the heart button underneath the image. A count of likes appears underneath images which all users can see. Likes on posts in this study were anywhere from 0-594. Likes function in this community as a form of validation or recognition. Likes are a key function on Instagram as a platform in that the more likes a post has, the more popular it is. This inherently creates a popularity aspect which probably feeds into user's motivations when creating posts and sharing them on the platform (Goodwin et al., 2016). While this likely played a role in the participant's motivations in this study, interview participants did not describe an awareness of the need or desire for high likes. However, those with the highest number of likes consistently posted and were developing personalities online with blogs and YouTube channels, which would suggest that likes were at least somewhat important to them. One participant, I will give the pseudonym Mary, stated,

Of course I am not able to say how many people see my posts and simply move past it. But posting does allow me to go back and see those that have liked and in some cases find other Instagram pages that are dedicated to the condition and also find other persons like myself that do have the condition.

This quote shows that likes are important in more than the popularity aspect of a post. Likes are a way to connect with others. When a user likes a post, their username appears which is linked to their profile. Therefore, the original poster can click on the names of those who liked their post

and viewed their profiles. In this way, as Mary explained, it helped to create the network that joins this community together. Likes are a minimal effort contact point between users.

### *Comments*

Comments function similarly on Instagram, in that usernames appear with the comment and the original poster can click on their name and go to their profile to view who commented on their post. Comments however, are also the main point of conversation on Instagram between users. Comments are where community members connect, give advice, and support.

Introductions were often found on comment threads which usually occurred by a member stating they were new to fibromyalgia or the platform and had questions about the illness. It was clear that many members consistently conversed in comments as they appeared to know each other. This is a critical part to the community as users are able to maintain connections by actually directly writing to one another and conversations can evolve to include many others as they view and comment on the post. Commenter's often tagged each other by putting a "@" in front of another commenter's username which links their profile so that they would receive a notification and return to the post to view the reply. Another key to comments was that they could also include hashtags, further widening the potential of the post's visibility.

An important part of the dialogue within comments included emojis. Emojis are emoticon type characters that can be used to express different feelings or themes in written text. They are often utilized in text messaging but can be included on social platforms, like Instagram. Emojis range from smiley faces to a multitude of different facial emotions and characters such as hearts, weather-related symbols and even food items (Apple, 2016). The most commonly used emojis in

the comments analyzed included hearts and two different faces that depict stress/anxiety, pictured below.



Emojis are important because they changed or developed the meaning behind certain words or phrases that users expressed in either captions or comments. Because emojis are well recognized by social media users and most individuals who have a smartphone, it was clear in the analysis that users were well versed in their meaning and routinely used them in conversations. They emphasized points and added levels of emotions possibly not included in the text, such as the heart emoji. This likely aided in the creation of bonds between users.

### *Followers and the Audience*

Each user on Instagram has a number of followers, which is displayed at the top of their profile. In this study, participants had anywhere from 23 to 9000 followers. Similar to likes, follower counts may be attributed to some popularity status, where a user with more followers may feel a sense of validation and one with little may not as though they have a popular account. With a private account on Instagram, users must request to follow the individual whereas with a public account anyone can instantly follow you. Only public accounts were studied for this study so that may skew the follower count slightly, in that it may be higher than a normal average, which sits between 100 to 200 for general Instagram use (Statista, 2015).

Interview data showed that participants did consider who they were posting for, or who their audience may be. Every participant said that their list of followers was primarily composed of individuals they only knew online and the few who had offline connections following them

were only at about a handful. For example, one participant stated, “I have about 6000 followers, and about 10 of them I know offline.” Therefore, the motivation behind posting is likely to share with this community rather than to connect with members they know offline. This gives more context as to how users post and what their motivations may be in sharing the types of posts they upload. It also gives a strong argument to how vital this community is, if members are focusing on the Instagram community rather than furthering their connections offline.

### *Messages*

Private messages were not analyzed in this study but these messages were the way I contacted participants for the study and using this function of the app made me recognize that there was another area of communication occurring on the app. Messages are an important element of the app because the function allows users to privately contact one another, either in a group or one-on-one message. Users will receive a notification if they get a message and can continue the conversation over time. The importance of this finding is that it may be a key to maintenance of relationships as members can possibly share more private information here, away from the eyes of all their followers. While no questions were asked about the message function, many participants responded quite quickly to my initial message in data collection, suggesting they are at least well-versed in this function. Having access to a more private space may also eliminate the need for community relationships to leave the app to connect. For example, why exchange numbers to text if you can do this on Instagram? Why go to Facebook to message one another if there is no need? While users may still exchange this information, if an organic connection forms over Instagram and there is an ability to move the relationship into a more

private space, it may be unlikely for members to exit the community to maintain it. This could be one hallmark to the sustainability of the community.

Private messages also functioned as a point of contact for individuals such as myself to contact those living with the illness. Just in the short period of time that I had begun using my researcher account and had some discussion of fibromyalgia on my profile, three users contacted me asking me to try out their various health products for good health and wellbeing. Other participants described this same phenomenon where individuals selling protein shakes, supplements or medical treatments would contact them on the app via comments and messages. This phenomenon is discussed further in the following section.

## **Forming a Social Space**

While the tools utilized on the platform managed to form the community, a desire to have a social space was a major reason individuals were drawn to the platform. This section will demonstrate how major lifestyle changes led participants to enter Instagram, thereby forming this community.

Interview data highlighted how much of a toll fibromyalgia had taken on participant's participation in their day to day life offline. It appeared that fibromyalgia symptoms kept participants somewhat at bay from actively living the life they may wish to live or one that is often considered 'normal' in our offline world. For example, participants wrote the following;

I've had to step completely back countless times and 'do nothing' and gradually add things to my lifestyle. This isn't natural for me to rest and I'm constantly pushing myself to do something. You have to choose wisely and prioritize what you 'need' to do and what can wait. Socially it's difficult because you feel that you are always cancelling, changing or avoiding people.

This year I had to stop professionally wrestling, postpone studying, my social life and stop fulltime employment, etc. I have been able to gradually increase my working hours and teaching but I'm far from being as active and busy before my recent crash.

With chronic pain and fatigue it makes it difficult to attend social events especially parties or activities. Also fibro sufferers like me, have anxiety/depression. So it not only makes it hard physically but also mentally. Even side effects of numerous drugs can cause a lack of wanting to do anything. For example you take these medications and want to attend a social event but at this event there will be alcoholic beverages. Alcohol overall can cause even more pain/inflammation without taking meds but now that you are also on these you shouldn't consume liquor. Which in some cases at these events like parties can cause you to feel like a bit of an outsider, which even worsens the depression/anxiety.

Each of these quotes highlights one or more activities that the participant has had to alter or stop due to their illness. The first two quotes show how the illness can make an individual have to actually stop working or studying and sometimes even force participants to rest when it may not feel like the natural thing to do. The last quote describes the compounding factors that can arise with fibromyalgia. The act of going to a party can be difficult on many levels for someone with the illness. This participant struggles with fatigue, pain, anxiety, and depression which can make a social event difficult to attend. Beyond physical symptoms, the side effects of medication can contribute even further to the difficulty of attending by causing weight gain or an inability to drink alcohol. These lifestyle changes proved to be challenging to those living with fibromyalgia and participants mentioned social circles decreasing and work or other activities being cut.

The lack of ability to participate in social events caused major lifestyle changes, which frequently arose within the data. This change seemed to have forced a shift in participant's offline worlds. Participants described this change as difficult to manage with friends, colleagues and family members. Only one participant described a strong support network of her boyfriend and mother. Losing the ability to participate in life activities was not just difficult on a social level but was an emotionally charged topic for participants. For example, one participant wrote;

I had a job I absolutely loved and I have always had 3 jobs on the go and been a really hard worker and to have that taken away from me has been the hardest part of this all. It feels like such a giant piece of me has been ripped away.

This quote highlights the identity shift occurring with living with the illness. Participants described feeling this way, as if a pieces of whom they were had been taken away from them, without permission, and they were forced to find ways to adjust to living without those pieces.

Another participant explained;

My illness has...eaten up my life. I have no energy, my depression has worsened. I can't play with my kids, or walk my dogs. I feel alone, left out and isolated.

This quote describes the root of the phenomenon expressed by so many of the participants. Not only did the illness cause lifestyle changes, it often caused serious debilitating mental distress. The isolation described in this quote was common throughout the responses. Participants often felt "left out" in their offline worlds, as though by not being able to take part in activities that required their physical body completely limited their ability to be a part of the community or society around them.

However, the disconnect between those with the illness and their communities was not just due to the lack of ability to participate in activities. Even when participants could complete the physical activities they wanted to, they still did not always feel as though that was enough to give them a feeling of fulfillment due to their illness experience. For example;

I push through pain to get up out of bed daily. So to finish out my day with a full time job, sports activities for my body and motherly duties. Then add on events, church and having to go out with family etc. My brain is not there mentally because its focused on the pain. That's an impact on my life and heart that I'm missing out on.

As this participant describes, even when one is able to complete all the necessary duties her social life includes, she is not available or present in the moment due to her pain. Mentally, the participant struggles to be as involved in her life as she wants to be, even when she is physically forcing herself to do so. As she explains, there is an impact on her life and heart that she feels

she is missing out on due to physical pain. Therefore, the impact of fibromyalgia appears to be multifaceted when it comes to lifestyle shifts and changes. Mentally, participants were forced to focus on their pain, but were also often left feeling vulnerable or down due to their pain stopping them from remaining in their community.

This presents one of the first motivations to join Instagram that arose in the data. While participants were not able to be physically or often mentally present in their communities that existed pre-illness, it did not mean they did not have the desire or ability to participate within community as a concept. Instagram became a site or source of community that participants were currently lacking offline. The first motivation I identified in the data was the desire to find or be a part of a community. It is important to note that while this motivation may suggest that one would only use Instagram if they did not have a community offline but it may not necessarily be true. As the earlier quotes suggested, some participants were still maintaining their presence in a community, it was just lacking the connection that they desired to achieve with others. Their online connection appeared to fill this gap.

When interview participants discussed their social ties offline they followed it with a discussion around the community that the participant had become a part of on Instagram. Participants were usually very thankful that they had found other users on Instagram to connect with in order to re-gain a social network where they could not only feel comfortable about their illness but also discuss it in detail. As one participant explained;

I think community is so important, especially when you have a chronic illness which can be very isolating. Knowing that there are people around the world that are going through the same stuff is very powerful and necessary.

While the community may never manifest in a physical sense, just having an awareness that there are others out there living with this illness seemed to be reassuring to participants.

Participants described finally being able to feel social again, which they may have lost in their offline world. Another participant, named Melanie, stated,

Fibro management is ROUGH!!!....My online fibro community I built helps me wonders. If I am going through something I put up a fibro post and others comment and relate it helps me a lot.

While this quote is similar to the previous one, in that Melanie describes how beneficial and important this community is, the quote describes more facets of the platform. For example, when Melanie “going through something” she can put a post up and have a response that makes them feel connected, and as though they are not alone. If they are feeling lonely or isolated offline, this tool may be very powerful for them. Further, the response may be instantaneous and as the previous quote suggested, from anywhere in the world. This aspect is very unique when comparing the offline and online worlds. For example, if a person is having a difficult night due to a lack of ability to sleep, extreme amounts of pain, or even spending the night in the hospital, they are able to log on and with an upload, receive support via likes and comments. This is not a type of connection that is possible without an online signal and as participants suggested, their ability to connect with those in their physical social worlds was hindered by their illness. The Instagram community has the ability to breach this gap.

The quote from Melanie highlights another important element of the relationship built between community members. Many users described their communities as spaces that they had “built.” This ownership was a unique element that may not be how we would describe offline communities. There was a general sense of pride that one’s Instagram account had gained such a community through followers, likes and comments. In fact, as this community was “built,” it was not a stretch for participants to refer to their group of Instagram followers as friends. The key finding here is that while users may have felt as their social world had decreased or as though they were socially isolated offline, they were able to re-create the feeling they had previous

experienced on a new platform, with a new social group. By rebuilding a social world, participants were able to experience connection and friendship which they may have lost offline.

One participant explained,

Although my followers on Instagram are people I don't know in real life and I may never meet, I consider them friends. Often, they know more than people in my life and they give me great advice.

Here the participant refers to their followers as friends, showing the heightened social connection Instagram provides.

Friendship was not the only way participants had re-built their lives online. Two participants described having blogs where they described their lives with fibromyalgia, but also recommended treatment remedies and further connected with other people living with fibromyalgia. While the blog was meant to continue to share journeys, it may also have been a strategic move on behalf of participants to work towards building a career online. One participant described actually creating a business online. As they wrote,

Yes, I have needed to cut back on my work to part time. I did start my own Scentsy business to help supplement my income. It's also given me the opportunity to make friends and show others with chronic illness they can run their own business.

Here, the participant explains that by running their own business online they are creating an example for others living with chronic illness if they have had to cut back on work, proving that it is still possible to continue to work. Scentsy is an online business model that sells retail perfumes, candles and other home lifestyle products, similar to an Avon business model. By using an online platform to create and maintain a job once again allows individuals to take back some of what their illness may have taken away from them. The online realm allows them to reconstruct lifestyle changes such as a building of a friend group or an income source.

Another example of creating a life online was when one participant talked in detail about the medical community reaching out to her on Instagram;

I have had some medical professionals, like doctors, as well as individuals selling naturopathic or protein shake products contact me. Some of these products I have considered trying, but I haven't yet attempted anything mainly due to money and I am a bit wary of their actual benefits. I have had conversations with pretty much everyone who has messaged me saying they are from the medical community or doing studies. Studies are rarer but like this one I knew I wanted to do instantly so I know my voice is heard. Doctors or medical professionals talking to me online I am weary of obviously but I am not in a position to turn down any help I can get!

Another participant wrote;

I've also had many professionals in all fields of medicine and homeopathy contact me.

These responses highlight two key details in the experience participants have on Instagram. One is that it is clear some members of the medical community, or those who say they are a part of the medical community, are reaching out to individuals who post about their illness experience online. This is an important finding that may be worth further research. Interview data suggested that most of these individuals had a product or treatment method that they were looking to see if the participants had considered or already done. Clearly, in these instances either these individuals may be looking to sell such products or may be contacting participants for research purposes. Participants who spoke to this phenomenon stated that they had not been contacted specifically for research about their illness experience or on their use of Instagram. Some had been contacted for recruitment of medical studies. If members of the medical community are utilizing Instagram to contact potential patients, this may bring up ethical concerns but could also be a beneficial tool that could be further developed in order to connect people with illness to faster or clearer medical advice. Another important note on this is that participants may be willing to even rebuild a doctor/patient relationship online, as they are building a community and even a workplace online.

When the physical, offline body is struggling, the online world may be a beneficial place to rebuild a life. Also unique in this interaction is that participants were given power to what

remedies, studies, or suggestions they respond to. They were also given options. As previous research has shown, individuals with chronic illness often feel at a loss when dealing with the medical community or working to find a treatment method that works for them. In this space, they were given power to choose what they try or whom they interact with. Again, this highlights the control over virtual space and time not found in the offline world where you must physically attend a doctor's office and often wait lengthy periods of time to see a specialist. Further, you typically are only given one or two options for whom you may see, due to geographical restrictions and financial cost. While participants are likely not engaging with medical specialists on Instagram, fibromyalgia is an illness (and there are many more) that lacks a clear cut specialist to see or a clear medical treatment plan. Therefore, to be given a space of treatment options and opinions may be a relatively new phenomenon to participants on Instagram. This may give participants a sense of power over their illness management and related decisions.

Lifestyle changes describe one of the main motivations for participants using Instagram. When participants found their social life diminishing offline and were not able to participate fully mentally or physically, the online space provided them with an opportunity to rebuild or make necessary lifestyle changes. The dichotomy of the offline versus online worlds is present here as a participant may have felt as though their body completely failed them in the offline world, and their presence was severely compromised. Physically they either could not participate, or mentally they could not focus. The online world not only allowed them to be present, but to be a part of social world and possibly a medical community or place of work. This allowed them to not only *create* a community, but choose how and when they participate in it. The next two sections will address how this community was built based around two goals; defining the illness and raising awareness.

## Publicly Defining Fibromyalgia

A major reason for using the Instagram platform that was identified within the analysis was that participants initially sought out Instagram to gain advice or ideas on how to manage their symptoms. This finding was not a surprise as many of us can likely identify with going online when we have a concern or question. It is not abnormal in our society to search for your symptoms online in order to identify the root cause of a malady or illness. However, fibromyalgia sufferers often appeared to turn to the online world when they were either in the process of being diagnosed or were recently diagnosed. As the literature review discussed, a diagnosis of fibromyalgia is often viewed as lacking in information (Madden & Sim, 2011), leaving those affected to search for information in places other than their medical advisor whether it be a primary care doctor, rheumatologist or other.

This theme was very apparent in interview data and one participant encapsulated this well. For the purpose of this example, we will call her Colleen. Colleen explained that when she was first diagnosed with fibromyalgia, she had not even heard the term before. The doctor gave her the diagnosis and suggested she try pain medication, more exercise, and healthier eating. The interaction was brief, and she left with many questions and confusion over who she could get treatment advice from. In her words,

So I walked out of the doctor's office more confused than ever and I felt like I had a doctor who didn't care about helping me get better. I started looking online and eventually found how many people were posting this stuff on Instagram. After a while I got comfortable to ask my own questions. I know that a lot of the remedies or food ideas that I found helped my own symptoms so it definitely is a good place to go for information. I didn't even think of getting a heating pad before I went on there and that changed my life by helping my pain!

Colleen's quote highlights a few important elements of this process and key points of the theme.

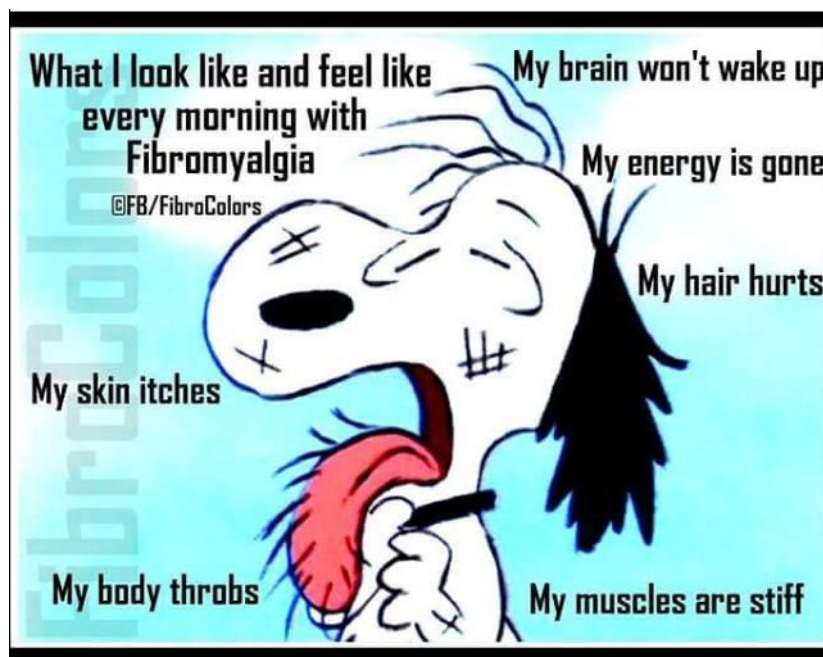
One is that many participants felt uncomfortable either going into more detail with their doctor

or they felt as though their doctor was not aware or not caring of their experience. While some participants mentioned having a supportive or caring health provider, many did not describe their health care experiences as positive or productive. This meant, as Colleen suggested, living with fibromyalgia often means having more questions than answers. Some participants were not even diagnosed and had questions about the illness, which was unsurprising, given the nature of the illness. Receiving a diagnosis can be a lengthy process, usually one that is focused on elimination of other illnesses such as Lyme disease or a variety of autoimmune disorders. During the content analysis of the posts, it was clear many comments were from users looking to try to figure out if they *could* have fibromyalgia or were in the process of trying to receive a diagnosis. Some of these comments included (often on posts that described symptoms);

Are these symptoms specific to fibro?

I have been experiencing symptoms just like this, plus chills and heat flashes. Do you think I could have fibro?

While it may appear unusual to some to ask a stranger on the internet a personal question about your illness, it was quite normalized among posts. Further, Colleen's explanation shows that participants come to Instagram looking for advice. It almost appeared as though participants were looking for the expert in fibromyalgia, as their doctors did not seem to give them the type of advice they felt they needed to maintain or manage their symptoms. For example, on a post of a computer generated image of the cartoon character, Snoopy, an interesting comment thread followed (*Image 1.3*).



*Image 1.3*

In the image, Snoopy is looking quite ill with a list of fibromyalgia symptoms surrounding him. Some of these symptoms include “my skin itches,” “my brain won’t wake up,” and “my hair hurts.” The comment thread on the picture included this exchange (with pseudonyms, Shelby and Lizzie);

Shelby: Oh my gosh! I have fainted many times and once on the bathroom too! I don’t know why but I’ve always thought that it’s because of fibromyalgia. Doctors really couldn’t tell why...do you think it’s fibro?

Lizzie: I have POTS and possibly Addison’s – but I don’t medicate. I often pass out standing up from a sitting position, BP drops a lot. I have cool showers – hot waters not good- and I have a shower chair. I recognize when it’s going to happen and get on the floor. Could be worth you getting your doctor to check these out?

Shelby: wow! Good to know, I’ll ask my doctor next time I see her. Thanks for the advice.

This thread of comments is typical of symptom related discussion. Many Instagram users appeared to be utilizing the app in order to gain information about their symptoms and other users seemed to become credible based on their own experience with the illnesses they posted about. Instagram users with the highest number of followers tended to be the ones most likely to

engage in symptom-related discussion and to give advice towards others about symptoms. On the most popular of these posts, based on the high number of comments and likes, many individuals left inquisitive comments such as, “Oh my god! This is exactly how I feel. Doctors couldn’t really tell me why, do you think it is fibro?” These types of comments were frequent and highlighted how Instagram served as a site for inquiry and advice seeking. Users often discussed the root of fibromyalgia symptoms and treatment methods within this category and posted and interacted with other individuals who shared similar issues.

Another computer-generated image broke down the different symptoms or illnesses associated with fibromyalgia, which is pictured below (*Image 1.4*).



*Image 1.4*

The caption on this post stated;

So many things, yet conveniently connected. When people say “you just need more sleep” try not to take that personally. There are a lot of things #healthy people will say to you that may come off as irritating but they don’t understand. Just as we want people to respect our health and lifestyle we should respect theirs and educate them. I

had a really exciting weekend, but between the cold, more hours being active than usual my body is trying to catch up. Sleeping A LOT which is foreign to me because I never sleep. I am #hopeful and #committed to figure out a #lifestyle regimen that helps. Sending you all much love! If anyone has any tips for me I'm open to them all!

Some of the hashtags on the post included; #ibs, #fibromyalgia, #cfs, #positivevibes, #lupus. The comments discussion included other Instagram users making suggestions for symptom management including use of a heating bag, bath salts, and essential oils.

This post brings back another point that Colleen's quote raised. Colleen explained important element of the experience on Instagram. She says that she *knows* a lot of the remedies she found on Instagram worked for her symptom management. This is a key finding as it highlights a part of the online sharing of resources that may not be found in a traditional doctor patient setting, and that is the trial and error aspect. The previous post shows how fibromyalgia is often interlinked to other illnesses, and the caption on the post describes how community members need to be confident in their understanding of their own symptoms and recognize that other "healthy" individuals may not realize this. By gaining information or medical advice online, participants were able to test out different types of treatment, without being told one or another was best. After trying a treatment out, they could post their own review of the treatment and contribute to the overall narrative being produced that describes fibromyalgia.

Many different types of treatment were discussed on Instagram and they were varied in their success. Colleen described two different types, food and the heating pad. A lot of suggestions included actual physical items such as a heating pad, tensor bandage, or brace. Other suggestions were around different types of diets; anti-inflammatory, gluten, dairy, or sugar-free, protein shakes, and paleo are some examples. As found in the content analysis, many of the posts about food would describe a product or diet and what it did or did not do for the participant posting. Comment threads would follow with a discussion on the product or type of diet. Thirty-

day food challenges were also common; where a participant posted about a diet others can try for 30 days and see if their symptoms are reduced at all. This was also common with elimination diets, where a person eliminates certain types of foods for thirty days and slowly re-introduces them back into their diet to see if symptoms either flare up or stay the same with the re-introduction. Instagram was a useful place to discuss these diets or test them out as it was often premised that a user could join a group trying to the diet and continually post on how the diet affected their illness, thereby going through these trial and error processes with others. Those utilizing the app for this purpose were able to test out treatment methods on their own time, and re-evaluate their illness on their own. Therefore, participants are not necessarily relying on pharmaceuticals or just one doctor's advice. Participants took a clearly active role in their illness management by sharing advice and trusting other's advice on their illness experience.

In some cases, feedback was even provided on certain medical specialists or primary care physicians who "believe" in fibromyalgia. Occasionally, users who were near the same geographical locations would compare their experiences of doctors and create lists of which doctors in the local area would listen and give advice on their illness. While this did not happen too often, it was likely due to how widespread Instagram is globally and the phenomenon of "doctor shopping" or online reviews of doctors is not new with this or other chronic illnesses (*see Barker, 2011*).

Pharmaceuticals were also posted on the app. Often the image would be highlighting the number of pills taken in a day with an image of a pile of pills, a weekday pill box, or a prescription bottle. Comments would discuss the dosage the poster was on or side effects of the pills. However, these types of discussion were very limited. In the data collection, only two images highlighted prescription medication, with limited comments (3-6) on these images. What

was common was a discussion of how to eliminate pain pills from one's diet. While it was clear some participants felt the need to maintain the pills, they were searching for other ways to manage their symptoms or in some cases discussing how they weaned themselves off the medication and felt healthier for it. For example, some of the comments on an image of a collection of pill medications included;

Hi, I was looking at tags for fibromyalgia and came across this post [of medication], I heard its lack of nutrients. There are some people on YouTube that are pain free since they do vegetable and fruit drinks every day.

Once I stopped meds and got them out of my system some things improved. The pills are meant to help us, but unfortunately often carry with it terrible side effects I believed were my diseases progressing. I didn't realize until I was able to stop the pills, but I feel better off them. I know this isn't an option for everyone and it's absolutely about quality of life. Whatever is best for the patient as a whole. I just wanted to share that I wholeheartedly understand what this is like being on so many medications and being ill. I made some personal changes and I've found some relief with my pain and symptoms. If you ever need someone to chat I'm here.

These pieces of advice, while possibly unsolicited, speak to the knowledge generated through lived experience that seems to be valued on the app. Members are included by way of illness and experience. Many comments ended with a similar line as the latter, stating that if the poster ever needed support, they were welcome to contact the member offering advice. These discussions developed the meaning of fibromyalgia by way of considering how to fix or help their fibromyalgia. For example, some of the most commonly suggested and successful treatments discussed on the app were; diets based on clean eating, heating pads and hot baths for pain, natural sleeping aids such as melatonin and resting when possible and/or necessary. These detailed suggestions help to give some insight into what the symptoms of fibromyalgia are (fatigue, pain, inflammation and insomnia) and how to possibly manage them to some extent. For the most part, it appeared that these comments and suggestions were welcome, even if they were not asked for. Conversations would develop through comment threads, allowing ideas to be

considered and discussed and often would form into agreed upon methods to help curb symptoms or find relief. This was one clear identifier of the formation of community.

## **Awareness**

Awareness was a key finding in that participants both used the platform to connect with individuals who were new to fibromyalgia but also to try to legitimize the illness. As fibromyalgia tends to be an unidentifiable and invisible illness, many participants did not feel as though it was publicly recognized as an illness in need of funding, research or recognition. Participants were not unaware that their contribution to the app could be viewed by individuals new to the illness, and took this responsibility seriously. The mentoring of new “fibro warriors” was taken with great responsibility and repeatedly came up in interview data. Interview participants routinely referred to other Instagram users with fibromyalgia as Fibro Warriors. This appears to be the adopted term within the group, highlighting a sense of pride and strength that the community holds for one another. For example, a participant wrote;

Connecting with other fibro warriors is a reminder that other people out there live this same life everyday and struggle the same way I do. We really are in a battle and it’s nice to know you aren’t alone and that other warriors are fighting for recognition as well.

Referring to one another in this way consistently reinforced that living with this illness causes one to be a warrior, and to mentor new fighters is also something to be proud of. This furthers the connection of community within the group as it shows the respect they hold for one another.

Interviews showed that participants routinely used Instagram to explain and show what living with fibromyalgia was like. They also used the platform to try to connect with users who were newly diagnosed to share resources and advice. Participants described wanting to explain

fibromyalgia to those who may not understand it and describe how it feels to have the illness. Participants were highly aware that by posting with this in mind they were not just contributing with an individual effort, they knew there was a collection of members sharing this goal and attempting to spread awareness. As participants explained;

I was so unaware of all the different invisible illnesses before I began engaging on Instagram and now I am a champion (or am trying to be!) for all of the different illnesses. Fibromyalgia affects people of all ages, races, and genders and there definitely needs to be more awareness for it. There are over 200 symptoms and each one is more horrible than the last and people have no idea what it entails.

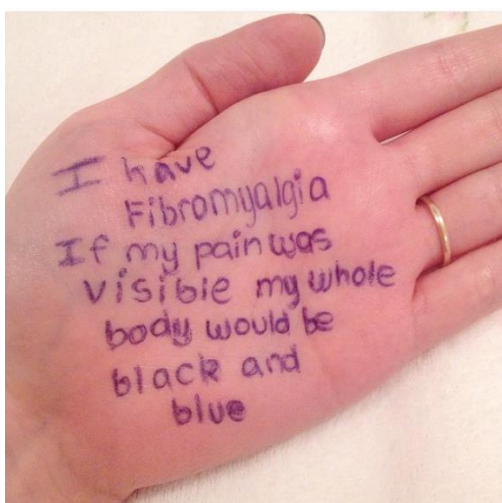
I choose to post images with the #fibromyalgia to heighten awareness of fibromyalgia. The images with the hashtag usually depict the way someone living and struggling with fibromyalgia can immediately relate to without being judged as well as being understood!

It has been great to be able to mentor other new fighters and help them through the diagnosis. I'm very grateful to Instagram for this!

There was a general consensus amongst the interview responses that it was important for the members to care about fibromyalgia awareness. Many participants felt a responsibility to newly diagnosed users who may need the support in their illness management and the more these users posted, the higher likelihood newly diagnosed were to see their community. As the first quote highlighted, participants felt confused and frustrated that fibromyalgia could have such an impact on each individual (over 200 symptoms) and yet there was little awareness about the illness. Some participants struggled with their feelings in that they felt they lived with a very debilitating condition and yet they did not feel as though they were taken seriously, or that anyone was listening. Those posting about fibromyalgia on Instagram were working to create their own narrative online and explain to others the reality of their experience, whether that was day to day life or symptom management. While participants mentioned that it was a way to have family and friends understand what they were living with, this was not the main motivation. It was more important that new members to the community realized that they had support and that any

members of the general population on Instagram could see their posts and learn more about fibromyalgia.

The most prominent (based on the highest number of likes and comments) post about awareness was from a professional sports player posting with the hashtag *#fibromyalgia*, whose younger sister lives with fibromyalgia. One of his posts depicted him and his sister being interviewed for a news story about fibromyalgia and charity events they were promoting to raise funds for fibromyalgia research. This post received the highest number of likes in the entire dataset, at 594. This is most likely due to the Instagram user's high profile as a sports player, yet it is an important finding as the post clearly has a far reaching audience. Another post (*Image 1.5*) describing awareness was that of an individual's palm with the words written in pen on it; "I have fibromyalgia. If my pain was visible, my whole body would be black and blue." The blue pen on the individual's skin creates an interesting contrast which highlights the nature of this illness. The hand, while it appears to be healthy, is covered in blue ink. The body, as the writing explains, may appear healthy when living with fibromyalgia but if the illness could manifest outwardly, this may be what the contrast looks like.



*Image 1.5*

While this post includes a description of pain written on the individual's palm, the caption underneath also focused on raising awareness:

#fibromyalgiapalmchallenge

1. Read about fibromyalgia. (FMS) ([www.fibromyalgiaawareness.com](http://www.fibromyalgiaawareness.com))
2. Write on your palm 'I know all about Fibro' or 'I have fibromyalgia' & something you have learnt about FMS
3. Take a photo your palm & share it with the hashtag #fibromyalgiapalmchallenge

This is the spoonie version of the ice bucket challenge to raise awareness for a horrendous illness that destroys lives & desperately needs more research so that one day we might be able to find proper treatment or even a cure.

I tag every person who sees this post. #fibromyalgia #findacure

A search of this hashtag (*#fibromyalgiapalmchallenge*) on Instagram revealed about 200 posts at time of data collection. The movement clearly did not take off on the same scale as the ice bucket challenge for ALS. However, the caption illustrates how social media can become a space for illness related advocacy and dialogue. That so many individuals chose to post a palm with this caption demonstrates that Instagram can serve as a space where people unite in supporting efforts to increase awareness of the illness. This follows in the footsteps of other more prominent awareness campaigns on social media, such as the ALS Ice Bucket challenge and Run for the Cure for Breast Cancer. These posts can be viewed as a prototypical effort that could eventually evolve into a wider trend in raising awareness about fibromyalgia on social media.

Other posts had a clear focus on education and explaining fibromyalgia to others, specifically "healthy" people, who did not understand the illness. One post had a photograph of a book titled "Breaking through the Fibro Fog: Scientific Proof Fibromyalgia is Real." The individual posting this was self-educating and many of the comments revolved around discussion of finding good sources to learn more about the illness or to give to people in their lives offline to teach them about fibromyalgia. Other members however, focused on the idea of how "others" or "healthy" people did not grasp their experience. A general agreement amongst members was

that it was often up to the ill individual to educate or explain their illness to these people in their lives. It is not an unknown phenomenon that those living with chronic illness have a difficulty connecting to those in their lives without illness. However, these discussions on Instagram suggest that it is of high importance or value for those with chronic illness to have others understand their experience and that some of the responsibility does fall on them to explain it. This helps to explain why users were motivated to try to raise awareness on the platform.

Interestingly, in the interview data, it became clear that there was something unique about the Instagram platform in terms of spreading awareness or gaining medical advice, as compared to other social media sites that made it the most appropriate venue for this community to form and maintain. When asked if users posted about their illness on other social media platforms, most often the other platform discussed was Pinterest, a social media site that allows users to search for a variety of topics such as recipes, lifestyle tips, and clothing. Each post on Pinterest is linked to a website where the image and description come from. However, the actual networking with other users on this site is limited as compared to Facebook or Instagram. Participants discussed using Pinterest to find information on fibromyalgia, as each post is linked to a website which may have further information on the illness. A few participants discussed having blogs, and one participant even sent me a link to her YouTube account where she posted videos discussing fibromyalgia. However, Instagram appeared to be the platform where the largest network of support was centered on. Facebook was discussed as well, but typically was criticized due to the responses participants had received. Participants described the other sites in these ways;

I used myfibroteam a few times but the site is set up very poorly and just freezes. It's kind of like a freezing fibro Facebook...so just Instagram [I use] for fibro posting.

I do use Pinterest as it does offer more insight into the condition, treatment, etc. So I do use that platform to learn and also find relatable posts but not so much to post of my personal experiences.

When people respond to my Facebook posts [on fibromyalgia], telling me about their friend's cousin's uncle who has fibro and how bad it is, and that they understand, it's very hard to maintain composure. Unless the fibro monster lives within you, there is no way to understand, Period. Instagram has linked me with other people with chronic pain, people who know the life and the exhausting reality.

These reflections show the importance of the Instagram community.

While participants focused strongly on the communal aspects Instagram afforded, the content analysis and descriptions of editing from interview participants suggested that the visual aspect of Instagram made it a unique platform to construct a visual of the illness. The platform afforded an inclusive experience that not only bridged relationships but also allowed for a representation of fibromyalgia not found elsewhere. The visualized aspects of Instagram made the platform ideal for the study but alongside the tools provided that helped to form relationships made it easily accessible for the formation of the community. It appeared that social media in general had become an outlet and a place where those living with the illness could actually be heard. Participants generally appeared to feel as though their posts were important to awareness of fibromyalgia and that this was a noble cause, to share about the illness and mentor those new to living with the illness. There was no doubt that the connections in the group had clearly brought them into a network of support and often provided resources, and these were signs that people were listening. For example, one participant ended their interview by stating;

By posting on Instagram, I get to connect and receive encouragement. I also think by sharing my posts, I am more likely to create awareness on fibromyalgia. After all post allowed me to find you 😊

## **Chapter 6: How is this Community Sustained? Insight into Factors that Maintain a Fluid Community**

The purpose of this chapter is to explain how a community on Instagram can be maintained and why this specific community appears to be sustainable. The beginning of the chapter will describe how both understanding and empathy appeared to be at the forefront of this sustainability. The chapter will then move into a discussion of how members of the community assume certain roles which helps the community to stay focused and work together to achieve the goals previously discussed. Finally, the chapter will end by engaging with the idea that this community is at the mercy of Instagram as a platform, and discuss how that appeared to actually help sustain the community rather than diminish it.

### **Empathy as the key to Sustainability**

While the formation of this community was based on the motivation to rebuild aspects of the offline world that were lost with the illness onset, the community must include elements that maintain the group. It appeared that the key to the sustainability of the Instagram community and connections was an understanding between participants. Participants often described their support offline as there, but not quite adequate enough;

Although my friends and family are supportive, at the end of the day they just won't fully understand it unless they feel it for themselves, mentally and physically! You just don't get it until you get it!

My mom and boyfriend are my rocks they offer me so much mental support...which helps more than I can explain...but I have so many others in my life who think it's in my head or I am a drama queen...Or they have called me lazy...It's hard to not let those comments get to you...

The support I have offline is skeptical and scattered. Most people offline look at me and question me in disbelief. The ones who believe my illness and believe my pain are the ones I see the most. My immediate household, which is my husband & my 2 sons who are 11 & 4. Some selected coworkers, that I work closely with and my sisters and parents!

Responses ranged on this topic, from having little to no offline support to describing a fairly supportive network (in the latter quote). However, not one participant described their offline support as fully adequate. As the above quotes highlight, while participants perceived the support they did have as helpful or beneficial, it was scattered, skeptical, or misunderstood. These quotes raise a point that was consistently brought up in responses. While partners, family members or friends may have provided support, it did not necessarily translate into understanding.

Participants often recognized that their family and friends were attempting to show as much support as possible, but they still did not feel as though their offline network understood, or could understand, their situation. Interestingly, one participant, I will call Anna, stated;

Of my Family/friends- while persons are sympathetic toward my condition, it being an “invisible illness” makes it hard for others to understand and know how to respond with sympathy. Not many have taken the time to research what I have or try to understand. It is more of if they see me in pain/having a flare they will offer sympathies during that moment however they are not able to fully understand what it is like truly on a daily basis. So their ‘want of support’ is there but the actual effort to take the time to learn what is happening, not so much.

This participant describes the support they have, but then explains a desired level of support. As the participant suggests, they would feel more supported if family and friends would learn about what having their illness means for them and how it will or does affect them rather than acknowledge it momentarily. This is common in regards to chronic illness as family and friends often have a difficult time accepting the chronic nature of the illness and those with the illness struggle to explain what it means to be chronically ill. As Anna suggests, in order to learn and understand about a chronic illness takes time, which not all family and friends may have realize that this is what the chronically ill individual wants.

Participants also described varying levels of medical support. Two participants described fairly positive doctor support;

I do meet with a rheumatologist about once every fourth months so I do have some medical support offline.

For the most part my general doctor is very understanding to my different needs but it can take a full month to get in to see him.

However, the other participants who described their medical encounters did not have such positive experiences. One participant summarized their experiences this way;

Finding a good fibro doctor is a nightmare...the doctor that is supposed to treat and manage my fibro is a rheumatoid arthritis doctor. But under my insurance all the rheumatoid arthritis doctors that are on my insurance do not accept patients with fibro. And that's bullshit. Talking to my primary doctor about fibro he says I should go speak to a psychiatrist about my fibro. Which makes me so angry I want to scream. Talking to my psychiatrist about my fibro flares and fibro fog has not helped at all. So I convinced my PCP (primary care practitioner) to allow me to do physical therapy for my chronic neck pain that goes along with my fibromyalgia. But once my physical therapy is over my fibro pain management will be almost impossible.

These were fairly normal descriptions of medical management of the illness. Issues were compounded from trying to find a doctor that would treat the participant with their fibromyalgia, covering the cost through their own finances or insurance and then trying different types of treatment. This tended to be a frustrating process for the participants and while this is often a focus of research on fibromyalgia, it was not the primary focus of the interviews. However, it did come up for about seven of the twelve participants and it was clear that this part of illness management should not be ignored. It appears to be a lengthy, frustrating and emotionally charged experience for participants. Importantly, it appears to be more of the illness experience than just something that needs to be done for illness management. For example, when participants discussed finding others who understood what they go through, they did not appear to just mean physically or emotionally, but rather what they have to go through to manage their illness. This includes frustrating experiences with doctors or insurance which can often occur due

to the lack of classification surrounding fibromyalgia. By finding individuals on Instagram who had their illness, they felt as though they had found individuals who also understood the challenges of finding a “good” doctor.

The struggle of finding support offline and issues like dealing with doctor’s appointments or insurance issues often led to a further need for support or understanding. This brought the analysis to discovering another motivation for participants finding themselves on Instagram. This community, as discussed earlier, did create a social environment often lacking in the participant’s offline realms. However, it also provided a space of understanding and support that may not have been as strong offline. Here are some of the ways participants described fibromyalgia community;

The difference is [between offline and online support] is that the people online truly get what I’m going through whereas my family and friends offline don’t know what it feels like to have your body fail you so spectacularly.

I needed people who knew exactly what I am feeling and what this pain is like. I also needed people who could put into words how frustrating this experience is when I couldn’t. I don’t think I can explain how alone I have felt at times and finding these people on Instagram was like a miracle. I am one of the lucky ones who does still work, is still pursuing her dreams and still has some very key understanding family and friend members offline. But these are people that *understand*, they aren’t just *understanding*- there is an important difference. It isn’t often you can meet individuals with fibro in your day to day but on Instagram there is an entire world of them at your fingertips.

These quotes point in the direction of what appears to be the key of the Instagram community that makes it sustainable and popular. What was lacking offline for participants was a sense of empathy. While they may have had supportive, or as the second quote describes, understanding friends and family members, they do not know many others with chronic illness. Instagram connects users who are sharing a very similar experience, and these similarities are enough to allow participants to feel comfortable and safe to discuss their experiences.

Interview participants further described these feelings of isolation offline. One participant described this process;

For a while I started to wonder if it was all in my head because everyone around me didn't get why I wasn't just getting better or couldn't just do things. I started to wonder if I was making up the pain, if I had some emotional trauma I wasn't recognizing but even on the days I probably should have been depressed due to pain, my mental state has always been very stable, I never feel really low, just frustrated from this experience. But doctors did not believe something was wrong and they still don't really. That can be very emotional for me, even after years of doctor's appointments, when I am feeling generally healthy, I may still cry when I leave a doctor's office if I feel ignored or like they don't think something is up with my body. It can be kind of lonely to feel like that. Talking to others on Instagram made me realize I was not alone in these feelings.

This experience highlights how Instagram provides a space of communication and empathy.

Users can connect with someone who has also felt stigmatized, or experienced odd symptoms, or met a doctor who they did not feel listened to them. Just as a community offline may be available to you instantly after you come home from work or through a phone call, all members have to do is post a picture or write a comment to be instantly brought into the community. Once there, they can share about whatever they are feeling in that moment or that day and other members are able to respond just as quickly. There is a wealth of support and advice to draw on as members can connect worldwide, eliminating time and space restraints found offline. By having so many potential connections available it becomes very likely users will speak with someone or be supported by someone who can relate quite closely to their illness experience, and empathy appears to be a motivating factor to continue to use the application for this reason. One participant explained;

Instagram is amazing for bringing people together who understand one another and can share treatments and ideas. I'm definitely a more positive person for having used Instagram for this reason. I know I'm not alone and isn't that the most important part of being alive?

## **Roles within the Community**

In most communities, it can often be possible to identify roles. Goffman in his work on dramaturgical performance described a set of discrepant roles and discussed how these roles work together to create a system by which certain roles are privy to different types of information (*see* Goffman, 1959). Drawing on this conceptual idea, I identified six unique roles within the community for persons living with fibromyalgia. These roles are based strongly on the content analysis, but draw also from interview data. While these roles are not necessarily centered on information giving or receiving they function in a way that allows the community to form necessary relationships and share information. This information highlights community sustainability because slipping into one of these roles may allow members to re-build their identities as well as show how the members function together. This helps to sustain the community as individuals know what their role is in the group and can likely aid in achieving a sense of purpose.

### *The Coordinator*

The coordinator functions as the center of the community. If coordinators were to be viewed in a group, they would numerically be a minority, but as individuals they likely make the strongest impact on the community. For example, out of the interview data, only one of the twelve participants would have qualified as a coordinator due to the way they described their use of social media and number of followers. The coordinator functions as the hub of community. Coordinators post the most frequently, and likely have the highest number of followers, likes, and comments. In some ways, coordinators may be the glue that holds the community together.

This is done through the upload of certain types of posts. For example, a coordinator would often post information or advice about fibromyalgia and symptom management. The coordinator may post about new research studies and urge their followers to ask their doctors about new testing methods or treatment ideas. Coordinators may even post lists of doctors in particular areas who “believe” in fibromyalgia. These members are very welcoming to new members of the community, responding quickly to new comments from individuals asking about fibromyalgia and they maintain relationships with followers within the comment section. Coordinators may sometimes feature other prominent members of the community in their posts, with images and captions describing the member’s contributions or journey. This move by the coordinator solidifies connections and relationships that can be made and maintained within the community as well as aids that member in bringing traffic to their profile, possibly giving them more support or advice. Coordinators are likely to be one of the first points of contact for a new member, as their posts gain the highest number of likes and are therefore often a part of the nine popular posts Instagram highlights for each hashtag searched. Once a new member seeks out a coordinator, they are able to follow through comment threads or members the coordinator has tagged in order to locate other community members. An example of a coordinator’s type of post is below (*Image 2.1*). The post is typical of a coordinator, in that it provides information on fibromyalgia symptoms or causes. The image is compiled mainly of words, but shows what appears to be a file folder on top of written words, likely used to provide some form of legitimacy to the claims being made. The text content refers to experts finding links between low serotonin and fibromyalgia, and the poster has posted a link on their Instagram profile so that anyone viewing the post could be taken to the article. By including this note on the post, the coordinator likely appears to be more legitimate and research-based. While users may or may not

follow through to read the article, they may view this post as an important piece of information to consider incorporating into their illness understanding.



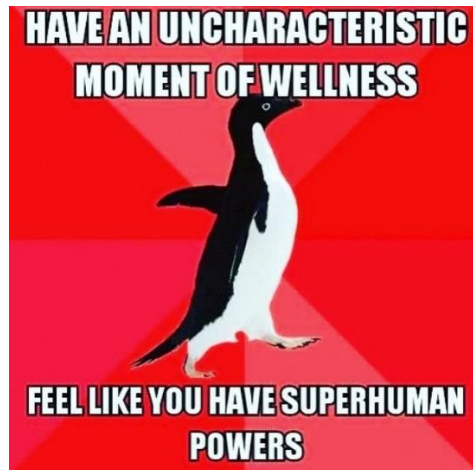
██████████ Could low serotonin be negatively impacting your #fibromyalgia symptoms? Read the rest of this article by clicking the link in our bio!  
 #fibro #fibrowarrior #fibrosucks #spoonie  
 #spoonieproblems #invisibleillness  
 #chronicillness

*Image 2.1*

Coordinators most likely spend some of the highest amount of time on Instagram and therefore it is likely to be a major aspect of their daily life. The Instagram community probably means a lot to a coordinator. Although coordinators are a small group of individuals, there is enough of them that if one were to stop posting or close their account, the community would continue to function. It is also possible that coordinators act almost in competition with one another, for the highest number of followers or to be the main “expert” of the group. However, all coordinators that were found in this study had upwards of thousands of followers, suggesting members follow multiple coordinators at a time.

### *The Motivator*

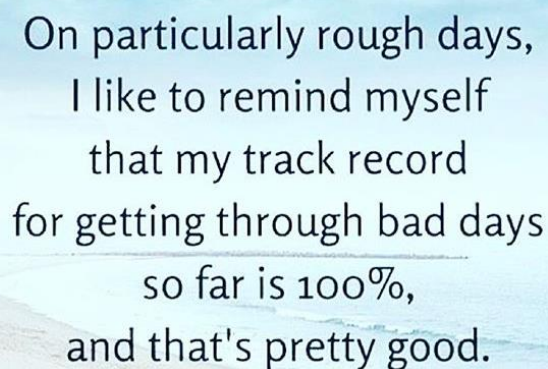
The motivator is like the coordinator; in that they have a high number of followers and post frequently. Also similar to coordinators, most of the motivator's posts were computer generated. However, the motivator only tends to post one specific type of image. This person posts both inspirational quotes and humorous images about fibromyalgia or living with chronic illness. The goal of the motivator appears to be a reminder that just because you are ill, it doesn't have to mean everything is bad. They focus on the reasons to laugh and to inspire one to live a full life even with chronic illness. The motivator highlights an important element to this community and that is the use of humor. Humor was often found in the use of fibro "memes." An internet meme is often described as some type of concept, catchphrase or media piece that spreads from person to person online, usually as mimicry (Gil, 2016). Participants said that they would post these jokes about fibromyalgia in order to bring some humour into the community. One meme that came out of the first stage of analysis is pictured below. The community may be built on a solid foundation of illness discussion and sharing of experiences, but they also insert humour and discuss daily life when it appears to be outside of their direct illness management, strengthening the bonds within the group as a community would function offline as well.



*Image 2.2*

Also, an important distinction from the motivator was the use of inspirational quotes or images to help push other members to continue focusing on the good in their lives rather than the pain of a chronic illness. An example of this type of post is below (*Image 2.3*). This image utilizes purple wording at the top which is a colour typically used for chronic pain or fibromyalgia awareness. The colouring behind the words is light blue fading into white and back into blue, depicting a sky with an ocean beneath it. In the bottom right is an entirely blacked out figure, walking along the water. This image is extremely bright, so much so that it is difficult to make out which highlights the black wording written overtop. The phrase and colouring highlight a sense of hope necessary to make it through the bad days associated with chronic illness.

## Chronic illness reminder:

A motivational reminder post with a background image of a beach and ocean. The text is centered and reads: "On particularly rough days, I like to remind myself that my track record for getting through bad days so far is 100%, and that's pretty good."

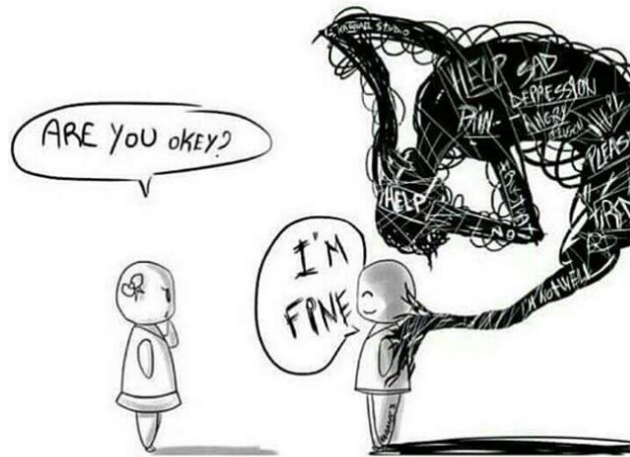
On particularly rough days,  
I like to remind myself  
that my track record  
for getting through bad days  
so far is 100%,  
and that's pretty good.

*Image 2.3*

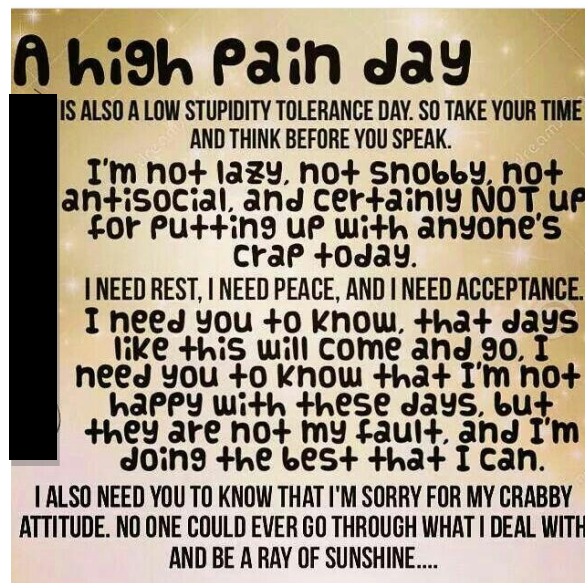
Motivators appear to want to bring joy and laughter to others lives as well as enhance others' well-being by posting reminders of how much strength it may take to endure the illness. There are a similar number of motivators as there are coordinators and they have a similar number of followers. Comment threads on motivator's posts are more likely to have many emojis or funny comments rather than more serious discussion of symptoms or treatment techniques. Motivators are engaged on Instagram quite frequently. Interestingly, two of the participant's I interviewed would be classified as motivators and they described their experience on Instagram similar to all other participants. While the coordinator discussed her follow count and her clear goals on Instagram to connect the community and mentor new members, the motivators discussed enjoying the connections and relationships the community brought them as well as how they were able to learn about their illness through others. This suggests motivators may often simply be posting images they relate to as well as motivating others at the same time.

*The One in Need*

The one in need is typically a new member to the community. This individual can often be identified by their comments on a coordinator or motivator's post, asking if their symptoms sound like fibromyalgia or asking other types of questions related to the illness. It is usually quite clear that this person is struggling. Often in their own posts, this person will describe having difficulty with keeping up in the offline world. Sometimes this individual is motivated to come onto the Instagram space after a difficult experience at a doctor's office or is trying to understand what fibromyalgia is or why their body is acting the way that it is. The main goal of the one in need is to gain a sense of support, validation, or recognition. They do not want to feel as though they are the only person going through this phenomenon and need to be comforted that others feel the way they do. In essence, this person does not want to be invisible any more. The level of interaction this member has is usually limited as long as they stay in the role of the one in need. Occasionally, established members may slip into this role when they have a flare up or end up in the hospital with bad symptoms and will post about the state they are in. Other members of the community often rally around the one in need and not only give advice and support but sometimes direct them to other resources. Coordinators always respond to these types of comments in order to aid the person in need. If a member stays in this role for a long period of time, they will often start to post consistently and the posts are usually quite sad or desperate in terms of the description of what the member is going through, with their pain or lack of offline support. Two examples of posts by a member in need are included below;



*Image 2.4*



*Image 2.5*

The first image shows two small figures in black and white having a conversation. While one figure is saying that they are okay, behind them is a blacked out, sketchy human filled with white words such as “sad,” “help,” and “depression.” Important in this image is the way in which the larger, sketchier figure is hunched over, possibly depicting the way pain can make one physically contort but also that this figure representing pain and depression is almost enveloping the small

figure. This highlights the monstrous qualities of chronic pain, and how overwhelming they are to feel. While the second image is mainly just a description with words, important here is the editing which utilized different fonts and sizes, likely to draw the reader's attention to different key words and points being made. These members are important to the group because they give the group one major purpose, which is to aid those in need. These members also show the serious side of the illness, the actual pain and struggling and the perceptions of the fibromyalgia that are often present offline. If these members stick around and become consistent members of the community, they may move through the difficult time they are in and use their experience to validate and motivate others. Many interview participants described how becoming a part of this community brought them to a stronger place both mentally and emotionally.

### *The Health Enthusiast*

The health enthusiast is a member who has become healthy despite their illness. When this member posts, their focus is almost always on health over illness. The health enthusiast may not necessarily have an active or consistent presence in the group (although they may) but when they do present themselves they are often a model for fibromyalgia. The health enthusiasts have overcome their symptoms because of a variety of health-oriented tactics. These tactics include: exercise programs, healthy foods, protein shakes, and various other treatment methods. Often, this member may not only want to inspire you to achieve the level of health or well-being they have but also to sell you a product or to bring you onto their team, which is a part of a exercise program or workout kit. Usually, the health enthusiast can offer other links to websites or videos that discuss the program or product they are promoting. These links automatically bring you to another place online, away from the community, and promote you on a different path. Health

enthusiasts stress that their goal is to aid in other's achieving their highest level of health as they appear to have already done. I was contacted by health enthusiasts after I made my account and inserted myself into the community. These members contacted me privately on the message function of the app. Below is an example of a typical post by a health enthusiast (*Image 2.6*). This image shows a variety of health products being sold by the poster, some of which create a giant neon green heart, grabbing the attention inwards. While the products are not necessarily large enough on the image to read, the poster utilizes emojis in their caption to coordinate with the colours of the image. Green is used in both the image and caption, likely to depict an overall impression of health.



[REDACTED] 💚💜 Let me share with you how these products changed the way I live with fibromyalgia and chronic illness.  
 💜💚  
 🥰 I've increased my energy,  
 🍏 improved my immune system,  
 ☀️ and decreased my general pain level.  
 💚💜 Invest in your health, invest in yourself, and FINALLY FEEL BETTER! Message me now!!! 💜💚 There's nothing else out there like it! So WHY WAIT?!  
 👁️ LOOK better.  
 💪 FEEL better.

### *Image 2.6*

This member functions in a few important ways for the group. They provide a counter narrative of someone actually managing their fibromyalgia through a variety of different ways such as exercise. They are also unique in that they are influenced by an external factor which is not family, friends, or stigmatization. They come to the group with a service to provide and self-market in the community. In doing so, they are using the community possibly for some level of financial gain and also to build their own business. This may be an opportunity for someone who is chronically ill to re-build their own lives online through this business as it may be a good opportunity for someone unable to participate in offline communities. However, with the number of health enthusiasts both in and outside of the fibromyalgia community on Instagram, it is probably unlikely these members do extremely well in the financial aspect of these ventures.

### *The Fibro Friend*

The fibro friend makes up the majority of the community. Fibro friends may come and go, but they make up the large portion of likes and comments on posts such as the motivators and coordinators. Fibro friends are not always in need, but they may sometimes slip into the role of being in need and then out again. Fibro friends ask each other questions and form relationships through comment threads and follow one another, growing the network. They often form these relationships through comment threads on coordinators and motivators posts. Fibro friends may post every day or only once a month with the hashtag #fibromyalgia. On their individual profiles, fibromyalgia likely is included in some of their posts but is a part of their narrative rather than their entire identity. Discussion topics between fibro friends range between doctor's appointments, symptom flare ups and lifestyle changes. While fibro friends may not post too

frequently, they likely have a decent number of individuals who post about fibromyalgia and many of them have made close bonds with a few members. Often, these friendships discuss other life topics as well such as friend and family relationships offline or discussion around work situations which bridges a gap between illness talk and general friendship important to common growth. While they may appear fairly casual in relation to the roles previously discussed, they in no way have a casual presence. Their discussion of fibromyalgia and the fluid relationships they hold make up the bulk of the community and keep the community active.

### *The Follower*

While this member is difficult to study and it is nearly impossible to know how many followers exist, it seems very likely that some portion of the members of the community are followers. The follower is someone who may have a private account, rarely posts or does not post at all about fibromyalgia but still follows some of the key members, such as coordinators or motivators. These individuals may have fibromyalgia or be linked somehow to the illness (maybe a friend or family member lives with the illness) and follows or likes these posts but does not participate in any other way. These members are still important to the community as not only do they raise the follower count on member's profiles but they also absorb the information the community brings forward. Therefore, followers help to maintain the community and are possibly benefited by the community without being recognized. Considering fibromyalgia can be a highly stigmatized illness, it is likely some members do not want followers on their account knowing about their illness, especially if their follower lists is composed of friends and family from the offline world. Therefore, they may not post or comment in fear of recognition but may still be a strong portion of the membership.

## **Fluidity as a Constant**

In regards to maintenance of the community, change becomes an important element to consider when analyzing a platform which is ran by a corporation, being Instagram. Changes are in essential to the nature of Instagram. In the process of doing this study, Instagram made three major changes to the platform which sparked media attention. Here are my field notes on the changes;

### *Platform Changes*

*March 30<sup>th</sup>, 2016:* I have noticed users posting with a standard image that encourages their followers to “turn on notifications” so that they will receive a notification when that user posts a photo. After researching online, I’ve discovered that Instagram has chosen to change their algorithm. Posts on Instagram have always been viewed in chronological order, meaning that when an individual scrolls through their feed of other followers, the posts appear in relation to the time that individuals posted them. This new change means that the Instagram algorithm will predict which posts appear to users based on which images they are most likely to like. Those images will appear higher on the feed.

Facebook already works on an algorithm system, which is not chronological but based on which posts users are most likely to like and want to see. Instagram stated that it will be weeks or months before the algorithm comes into place but that they will be testing it out for a while on certain users who will not be informed that they are in the test group. Reviews of this change are

largely negative, many stating that they appreciate the platform for what it is, and essentially, do not want another Facebook.

While this change won't directly impact my research, and doesn't appear to be affecting the users I have selected for study too greatly, the interesting element is how this affects community. When maintaining a community online, users are investing a level of trust or commitment to the platform they are communicating on. This trust is at the mercy of the platform which belongs to a corporation and can change at any given time. Further, if the commitment or communication is only on the specific app and users haven't revealed personal information or other ways of communication (phone number, email, address, etc.) if anything is to happen to their own account or platform, they could completely lose that community in a matter of seconds. As this change highlights, this online space is fluid and privy to a multitude of changes, many that can impact those users greatly. When dealing with an illness community, the nature of the relationships may be sensitive and crucial, which highlights the importance of recognizing these challenges as critical to the community.

*May 11<sup>th</sup>, 2016:* Today, Instagram unveiled a new logo for the application. The old icon for the app was a design that looked similar to an old model of a camera and the new one has a much sleeker, colourful design. Once opening the app, the whole platform looks different in that it is now all in black and white with only photos being in colour. While this doesn't change much about the functionality aspect of the app, across the internet reviews are not very positive. Most articles stated that the brand had been recognizable based on their logo and that this new look was very similar to many other applications already in existence. Interesting to this study, while this change probably will not affect the fibromyalgia community in any way, it is the second platform change Instagram has made during the course of this study (the other being the

algorithm). As discussed, this relates to the way in which the community is at the mercy of the brand and platform with little to no control over what happens to the app. These minor changes may be reminders to the community that their control on the app is very minimal. Changes to the platform have the ability to greatly shift or alter the community and the way it maintains connections. This disconnect may be interesting to explore further in interviews as to whether or not individuals connect with others in the community off of Instagram or if the app disappeared, would the community as well?

*August 10<sup>th</sup>, 2016:* Instagram has recently introduced “Instagram stories,” which is a new feature of the app that rivals their social media competitor, Snapchat. In their press release, Instagram describes the feature as a way to let individuals share the moments of their day, not just photos you want to keep on your profile. The idea behind stories is that users do not need to worry about “over posting” (Instagram, 2016). With this feature, a user can take a photo or video, add to it with text and drawing tools and then post the image for 24 hours, after which it will disappear. The stories of the people you follow appear at the top of the home screen as circles as well as with a circle around the poster’s profile photo. All a user has to do is click on the circle and the user’s images or videos appear on your screen. In order to comment on the story, you send a message through the private message function. Instagram describes this change by saying, “Instagram has always been a place to share the moments you want to remember. Now you can share your highlights and everything in between, too” (Instagram, 2016).

In regards to the fibromyalgia community, this may have a major impact on the way information is shared. The stories allow users to share instant moments and this may help members to share their illness experiences to an even more personal length, for example, posting a snap on their story as one is in the doctor’s office. It may function as a way to get to know one

another better by posting videos describing daily events. The story function has come in at a time when my data collection is complete, but this platform change is likely to somehow impact the community and possibly enhance relationships.

### *Chronic Illness and Fluidity*

As previous research as well as the interview findings in this study highlighted, living with chronic illness can be challenging, unpredictable and even chaotic. Planning can cause individuals affected by fibromyalgia to stress due to the unpredictability of the flaring of their symptoms. Many interview participants described the difficulty of keeping up with different events or spending time with others offline. Therefore, seeking the level of support found on Instagram offline would be extremely challenging, likely impossible. Offline support groups are often planned and meet in certain locations in a group setting. For someone with a chronic illness, to be able to attend a once a week or month group in a specific location could be a stressful task and one that would be entirely dependent on their health on that date and time. Therefore, having access to a space that has no requirement of time, place, or amount of participation appears to be very beneficial. Participants can enter into the community from the comfort of their own home or bed, or when they are sitting in a doctor's appointment. This allows for feedback, advice or support at the time that it is most needed, rather than waiting for a certain time or place to share. Further Instagram has part of the word *instant* in its name. This aspect is important in that members of the community can share their story or illness experience as it happens and when doing so, they are often guaranteed some level of feedback. However, they can pick and choose when they take time to share their story and when they participate in giving feedback to another. This fluidness of the platform and community, while a foreign aspect

to offline communities, is actually quite compatible to the experience of chronic illness. This fluidity is almost essential to the maintenance or sustainability of Instagram.

Due to the fact that there is little to no expectation that one's contribution to the community may lead to the idea that this community cannot maintain itself. Similarly, the fact that this community is held on a platform and is essentially at the mercy of this platform, could limit its growth or sustainability. This is highlighted in my field notes as I describe how these changes have the potential to alter the community. However, it appears that I was incorrect in this as the community instead, thrives on these factors likely due to the strong compatibility of life with chronic illness and a fluid community. Interview participants described a lack of ability to participate in their offline communities but a strong need or desire to stay in a community as this experience was isolating. Members of the community can disappear off the platform without establishing lasting bonds through a phone number or links to other social media account but the sheer number of members can maintain the community even when losing members. This fluid or flux aspect is built into the very structure of the community (i.e., the platform). It is meant to move quickly, to have fairly fast responses and to be essentially constantly changing. Therefore, while this version of community may not be one we can even visualize offline, it has evolved traits that have made it incredibly beneficial to these members.

## **Chapter 7: Discussion and Conclusion**

This concluding chapter summarizes key findings from the study and reflects on the purpose and importance of the Instagram fibromyalgia community for its users. Finally, a discussion of the limitations of the study is presented as well as suggestions for future research. The chapter ends with some brief concluding thoughts.

### **Summary of Findings**

Overall, the study's findings suggest that people with fibromyalgia make sense of their illness in two important ways. First, participants described the Instagram fibromyalgia community as instrumental in giving meaning to their "empty" diagnosis (Madden and Sim, 2006, p.2966). Second, participants described this community as an important resource to contest stereotyped and medicalized understandings of the illness.

### **Giving an Empty Diagnosis Meaning**

A diagnosis of fibromyalgia is a mixed blessing for individuals with the illness, in part because they are provided with insufficient information about treatment and prognosis, thus making their diagnosis an empty one (Madden and Sim, 2006, p.2966). When participants raised the topic of diagnosis in posts and interviews, many pointed to the challenges of getting a diagnosis and, later, sorting sparse or contradictory information about the illness. One interview participant sums up this issue well:

How is anyone really diagnosed with fibromyalgia since there isn't a diagnostic test rather a long process of elimination of anything else that they could possibly test for. I've had symptoms since I was 11 years and I'm now 32. I've done the push and crash cycle all my life as I was misdiagnosed, labelled and ignored the pain and symptoms.

How do you know what "normal" feels like if you've never felt "normal"? It's only recently that I'm learning to listen to the whispers of my body and understand it. Still to this day I will hear people within the medical industry say that I do not have the illness, or that the symptoms I have do not fit the diagnosis.

Several participants posted similar comments which corroborate findings from literature that describe the process of being diagnosed with fibromyalgia as unclear, confusing and difficult (Madden & Sim, 2006; Soderberg, 1999; Skuladottir & Hauser, 2008).

With fibromyalgia perceived as an empty diagnosis, many participants spoke of turning to Instagram in search for more information but also to share with others their less than satisfactory experiences of being diagnosed. As participants noted, the Instagram platform allowed them to meet others with similar experiences, converse and form relationships through tools such as hashtags, likes, follows and comments. These tools allowed participants to stay in contact on the app irrespective of whether they knew each other offline.

As a platform, Instagram allowed participants to create their own narrative and share personal experiences on their profile as well as to read other member's stories at any time and place. In relation to other platforms, Instagram seemed to offer additional benefits. Participants noted that while Facebook affords a larger space to share and write lengthier narratives, Instagram's visual and captioning features gives the app a more communal feel and a safer space with less negative feedback. In creating meaning about their diagnosis, participants also reported Instagram as a user-friendly platform which allowed communication to occur without the limitations of space and time. Participants in pain specifically reported this as the most beneficial feature of Instagram. Within a matter of five minutes, they could share their symptoms, find multiple other members going through a similar experience, and even strike up a conversation. In this way, participants found validation as sufferers of fibromyalgia but also actively contributed to this narrative by sharing posts about their own experiences and struggles with the illness.

Participants also created meaning about fibromyalgia by crafting a multitude of images and complex representations of the illness which they shared on the platform. Posts ranged from treatment approaches to selfies to weather-related images depicting emotions. They often centred on descriptions of pain, treatment options, emotional impact of living with fibromyalgia, and how to mediate relationships offline once diagnosed with the illness. The meaning conveyed by these images was varied, but ultimately described the reality of living with fibromyalgia on a day-to-day basis. Participants expressed the daily reality of fibromyalgia as devastating, challenging and occasionally rewarding.

Overall, postings on Instagram represent an effort on the part of participants to construct an identity online which derives from, but also differs in important ways from their offline identity. Due to the anonymity of Instagram and its highly visual medium, participants often sought to highlight parts of their body which were symptomatic, or displayed emotions by proxy by uploading images of stormy weather, or generated composite and sometimes disturbing images of bodies to explain what it felt like to live with this illness. In this manner, online embodiment appeared as a central feature of this meaning-making process and defined much of the participants' activities on the Instagram fibromyalgia community. This process allowed them to mitigate the emptiness of their diagnosis by developing their own narratives in relation to others in the community. These narratives gave meaning and clarity to the diagnosis in a way they could not find offline, which in turn contributed to reduce their sense of stigmatization and isolation in the offline community.

## **Finding Support and Resources**

The study identified three key reasons as to why individuals choose to share their experiences of fibromyalgia on Instagram. First, participants described their offline support as inadequate or scattered and expressed a desire to belong to a stronger and more cohesive community. The Instagram community not only filled this gap in offline support but also fulfilled a need for information which they were unable to obtain from doctors or specialists. For these reasons, many participants felt grateful that their diagnosis of fibromyalgia allowed them to participate in Instagram as members of a well-defined and resourceful community. Participants welcome their acceptance as members of this community, which they embraced by using the fibromyalgia hashtag for most of their posts.

With access to this community, participants said they were able to revitalize social lives, find ways to work, access medical information, assume new roles, and in essence, re-build an identity both online and offline. Participants singled out Instagram as a fluid platform with no requirement of long-term commitment or membership. While this may not be ideal for an offline community, having little to no requirement of participation gave participants a sense of ease and comfort when posting on the platform. This community also functions in a way that does not require the members to be held to an expectation of how often they post or participate; in this way, it is well suited for those with fibromyalgia whose abilities to contribute can often be diminished by the illness' unpredictable symptoms. Participants also noted that changes occurred frequently with old members leaving and closing their account but new members joining all the time. Instagram thus appears to have given participants purpose in their daily lives—they are beneficiaries of this community but also engaged with it by contributing to an evolving narrative about fibromyalgia that can be accessed at any time by users as well as newcomers.

Participants also used the Instagram fibromyalgia community as a forum to discuss the contested nature of their diagnosis. This was reflected in the many posts where participants talked about their encounters with the medical community. Their comments suggest a shared understanding of the need to challenge stereotypical beliefs about fibromyalgia as an unknowable, unreal illness. In particular, several participants drew attention to the lack of public knowledge of fibromyalgia and the need for more research, funding, and public support for the illness. In this regard, this finding suggests that social media can provide a voice to those with less power to challenge institutionalized knowledge about this illness. For example, one interview participant explained, “Fibromyalgia isn’t really well known or taken seriously, at least here we can start to change that and hopefully it will spread.”

Many posts widely shared among participants contested medicalized understandings of fibromyalgia. Thus, while Instagram offers a cathartic outlet for individuals with the illness, it also seems to serve as a vector of change once we consider the massive audiences the app reaches in a way not possible for the medical or offline communities. Participants mentioned bringing these alternate views to medical appointments, and sharing them with friends or family members offline. This finding highlights the unique and powerful offline influence of Instagram as a community. This community offers information, explanations and support without institutional planning or even grass-root organizing as in the case with offline support groups. This type of organic movement no doubt sheds some light on our understanding *how* a diagnosis becomes social and *why* institutional power dynamics may actually continue to push those with fibromyalgia to seek out alternative forms of information about their contested diagnosis.

## **Instagram as a Unique Community**

By understanding the way this community develops and maintains itself online, we can highlight the immense possibilities the online realm affords people with chronic and debilitating illnesses. The connections formed through Instagram community are simultaneously global and instant. A member in Canada can meet and construct their relationship with a member in Britain within seconds. Members can present their story through their profile of photos and share possibly the most vulnerable aspects of themselves (their illness) with what in the offline world would be equivalent to a stranger. Such intimate relationships or representations would be challenging, if not entirely impossible to achieve offline, where people in social spaces are often confined to displays of the self through hair style, fashion and manners. While we have the ability to modify our body's appearance, this comes at considerable costs and time, e.g., dying of hair, exercise, plastic surgery, etc. Yet, individuals can easily modify representations of their body in virtual space by manipulating images in unique ways which are not possible offline. This study revealed that participants spent long amounts of time editing and constructing their posts before presenting themselves on Instagram. They altered their appearance or used entirely different characters to present themselves. They represented their body or symptoms online by creating visual displays in ways not possible offline (the invisibility of fibromyalgia). In particular, emotions and physical symptoms were expressed with a vast array of imagery.

In this sense, human activity on social media is more than an extension of the offline world. While there are similarities in the way humans act online and offline, the online world provides many opportunities simply not available offline. Online, people find new ways to act and interact that either uniquely extend online behaviours or represent entirely new forms of

expression. For example, if an individual writing in capital letters while texting, or on Instagram conversations, the consensus is that this represents yelling or screaming of anger, excitement or shock. This replicates offline behaviour, i.e., the individual receiving this text deciphers the context of the conversation to determine what emotion is being expressed, which is not much different from what occurs in offline interactions. In contrast, the use of emojis found in this study exemplifies how online interactions can be vastly different from those offline. First, using emojis in offline interactions is obviously not possible. Second, while emojis replicate some facial expressions, their use is complicated by the sheer number of them and the different meanings attributed to each. When used to connect with someone through text, emojis can change and alter the meaning of words in a way that must be understood differently than in a face-to-face conversation offline.

Gaining familiarity with these types of nuances throughout the course of this study forced me as a researcher to stop making comparisons between the offline and online world. I concluded each space should be explored on its own merit. This is not to say that we are different human beings when we engage online, but sociological theory developed to analyze offline interactions nonetheless requires significant adaptation to study the online world. As this study shows, the online world is marked by fluid interactions whereby individuals reconstruct their identity and body using virtual technologies. Further, while privilege and power still exist in this space, how one looks online can equalize differences across gender, financial status, and health status in ways not possible offline. In that sense, this study highlights how evolved forms of relationships and communities are possible online. This is an aspect that should be increasingly considered as new social media technologies become part of our daily realities.

## Is Goffman Still Relevant?

Pinch (2010) draws on Edgerton's work to argue that while online technologies might be perceived as ubiquitous and mundane now, it would be a mistake to consider them sociologically uninteresting. Pinch (2010) remarks that:

Goffman liked to end each piece of his writing by reminding his readers of the fragility of social life as we poor humans do our best to play our roles and find and negotiate our fractures selves on the stage of social life. That the technology of the internet seems to have made this human project even harder reminds us of the profound insights in which Goffman has to offer (p 424).

Pinch (2010) further argues that researchers should be careful about theorizing online and offline spaces as being entirely separate, and seeing online interactions as completely different from their offline counterparts. He bases this argument on Goffman's (1959, 1961) discussion of mundane technologies, namely the merry-go-round and surgical tools, as well as the materiality of objects such as a door. Goffman argued that these technologies position individuals in different proximate spaces, thus mediating how they interact with each other. For example, a child on a merry-go-round is positioned closer to other children than her parents, thus modifying the interactional order of the parental relationship. Likewise, a surgeon and nurses are mediated in their interactions by the task at hand, namely the surgery to be performed.

However, Pinch calls for sensitivity in applying Goffman's ideas to study the online world. I agree with this position. First, not only are online interactions mediated by social media platforms, they simply would not occur without a technology that could hardly be characterized as mundane. Specifically, participants in this study would be unable to access the Instagram fibromyalgia community without a smart phone or personal computer, complex fibre optic

networks that constitute the internet, and the development of a widely-used and recognized social media platform.

The sheer complexity of these technologies has implications not only for how we conceptualize online interactions, but also for the ways actors access front and back stages. Participants in this study largely acknowledged that their offline front stage performances were mostly guided by a desire to hide their fibromyalgia due to its stigma. In contrast, these participants also spoke of using their online front stage to reveal their fibromyalgia in an open and honest manner. Using Goffman's (1959) analogy, one could argue that on the online front stage, these participants performed in front of an audience of unmanageable size given that their posts are potentially visible to 300 million other users. This is simply not possible in the offline world. Where then is the backstage to this unique front stage? Ironically, perhaps, it occupies a private offline file on a computer or smart phone where users construct their posts, chose and alter the images they upload, and craft careful responses to their followers.

Social media thus seems to have resulted in the development of new norms, new behaviours and even a *new mundane*. Using hashtags or scrolling through over 100 emojis to choose an accurate meaning to add into a conversation constitute new forms of behaviour and communication that must not be analyzed as replications or repetitions of offline human behaviour. The technologies of the internet and social media have thus given us opportunity to evolve community, relationships and even ourselves. This study convinced me that the online realm has resulted in the invention of a new social space that allow us to re-build our bodies and identities may warrant such as well.

## Research Limitations

While this study was successful in answering the research questions it initially posed, there are several limitations worth mentioning. First, data collection took place in a specific time frame, as necessary due to thesis deadlines. This means that a range of factors such as seasonal elements affecting the illness or peak times for posting were minimally addressed in the data collection stage. Further, Instagram is a fast-paced, instantaneous platform on which it is difficult to collect representative samples. While 50 posts and 12 interview participants is a decent qualitative sample size, with 200 000 posts about fibromyalgia being uploaded every 3 to 4 days on the platform, increasing the sample size in a future quantitative study would allow for more generalizable results on the Instagram fibromyalgia community.

Demographics such as age and gender were not considered during the analysis. This was due to the fact that it is next to impossible to determine the age or gender of the participants from the posts they put on the app. While demographic questions could have been included in the interview portion, I opted not to ask participants to ensure further anonymity. However, fibromyalgia most often affects women and based on my analysis, I believe only one participant in the study was male. Further, geographical location was also not considered in the study although this could be beneficial in understanding how culture shapes fibromyalgia symptoms and experiences.

Finally, due to ethical constraints, only public Instagram profiles were studied. There are likely many users with private accounts posting about fibromyalgia as part of this community. These users could have more offline followers and different insights about the online fibromyalgia community. It would be beneficial to examine private messages exchanged among

community members to determine how this group of users operate in what is otherwise a very public community.

## **Suggestions for Future Research**

Future research could look into other types of illnesses and the associated online communities that have formed and the type of information and meaning being produced within these groups. One possibility is the social media platform Pinterest, which several participants identified as one of their main sources of information about fibromyalgia. A search of the Apple App store reveals many fibromyalgia support apps. It may be interesting to study these apps to see whether they are as popular or function in a similar way as Instagram.

As this phenomenon continues to grow, it will no doubt be necessary to remain open to the necessity of understanding the online world on its own terms. Sociological theories or conceptual ideas around community, self-presentation, identity and embodiment may need to be re-developed or re-imagined in order to understand how technology has altered our current reality. Instagram is home to over 300 million users; yet, the sociological literature on this platform is limited. This is likely no longer a trend but a phenomenon, where individuals are extending their physical self using their fingertips and a new technological space. The space has many facets and evolving forms of communication that could be more deeply engaged in future research.

## Potentials for Technological Development

In their white paper on the current state of fibromyalgia in the medical field, Arnold et al. (2016) outline a variety of strategies to develop clarity and standardize practices across the field of fibromyalgia. In regards to standardizing diagnostic and educational levels across the medical field, advocacy, and creating regulatory pathways for treatments, many suggestions are raised. A few of these include;

- Promote awareness and access to resources developed at the national level that provide practical approaches to disease like FM. Examples of such resources include print-based articles, simple online tools and lectures, workshops, and presentations organized by speciality societies
- Establish or identify a credible global organization to serve as the flagship for FM education, advocacy, and changes to practice
- Create a website for doctors and another for patients containing the most relevant education and scientific information pertinent to each group
- Create a national databank on FM with the participant of interested physicians from academic, public and private institutions (Arnold et al., 2016)

In response to these suggestions, I suggest that social media platforms would be an excellent aid to meet these ambitious goals. As this study highlights, there already exists a high amount and variety of information online about fibromyalgia but to synthesize and provide this information in one or two social media applications could aid both patients and physicians. If this application was run by a global organization, regulatory functions and monitoring could be undertaken to be sure that a standardized level of information was being shared with all members. By opening up medical information to the public, relationships between physicians and patients may be strengthened as patients could possibly receive more reliable information than currently found online and physicians would have access to the narrative of fibromyalgia already being developed online. Further, social media apps provide an interactive, innovative and easily altered platform which has been shown in this study to be beneficial to those living with fibromyalgia

and may help raise awareness in an appealing way. While the goals outlined in the white paper may be ambitious and likely to be met over a long period of time, organizations already in place to aid those living with fibromyalgia may consider adopting a stronger social media presence to work to achieve these goals faster.

## **Concluding Thoughts**

This study privileged the voices of those living with fibromyalgia. As discussed, the diagnosis of fibromyalgia has been contested and debated over the last few decades. During this time, many have been diagnosed without understanding the full implications of their diagnosis. This study found that the experience of living with fibromyalgia is highly personalized and can result in confusion, stigmatization, and marginalization. While these findings are not new, the study described a growing online community that has emerged out of this isolation and is now working to define the illness on its own terms away from medicalized explanations. As shown, members of this community share what symptoms feel like, which treatments work, and how to access information and resources necessary for illness management.

The study's findings contribute to knowledge in the sociological and medical field through an explanation of how fibromyalgia symptoms manifest and are related to a variety of factors such as stress and weather. The findings also contribute to the medical field by highlighting the importance of clarifying and sharing medical research findings on fibromyalgia on a wider scale. Social media may be a place where the medical community can not only better understand individualized experiences of fibromyalgia but also report on recent research and support available to those suffering with the illness. This could aid doctor-patient relationships

for those living with this chronic illness and others. Further, the study shows how a diagnosis can be developed on a public, social platform and remain linked to political and cultural meaning. Finally, what should not be lost is the intricate way this phenomenon is tied to community member's lives and identities. As one participant summed this up: *"If I could give anyone recently diagnosed advice, it would be to **post your journey**. One day you will look back and realize how far you've come."*

## REFERENCES

- Agger, B. (2014). Hegel's Internet. *DisClosure*, 23(1), 47-64.
- Anderson, S. J., Dewhirst, T., and Ling, P. M. (2006). "Every document and picture tells a story: Using Internal Corporate Document Reviews, Semiotics, and Content Analysis to Assess Tobacco Advertising." *Special Communication*, 15, 254-261.
- Apple. (2016). *Use emoji on your iPhone, iPad, and iPod Touch*. Apple Inc. Accessed from: <https://support.apple.com/en-us/HT202332>
- Arnold, L. M., Choy, E., Clauw, D. J., Goldenberg, D. L., Harris, R. E., Helfenstein, M., Jensen, T. S., Noguchi, K., Silverman, S. L., Ushida, T., and Wang, G. (2016). Fibromyalgia and chronic pain syndromes: a white paper detailing current challenges in the field. *Clinical Journal of Pain*, 32(9): 737-746.
- Arnold, L. M., Clauw, D. J. and McCarberg, B. H. (2011). Improving the recognition and diagnosis of fibromyalgia. *Mayo Clinic Proceedings*, 85(5): 457-464.
- Asbring, P. (2001). Chronic illness – a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(2), 312-319.
- Asbring, P. and Narvanen, A. L. (2002). Women's experience of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qualitative Health Research*, 12(2), 148-160.
- Ball, M. S. and Smith, G. W. H. (1992). *Analyzing visual data*. Thousand Oaks, CA: SAGE Publications, Inc.
- Barak, A., Boniel-Nissim, M. and Sular, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behaviour*, 24(1), 1867-1883.
- Barker, K. (2002). Self-help literature and the making of illness identity: the case of fibromyalgia syndrome. *Social Problems*, 49(3), 279-300.
- Barker, K. (2005). *The fibromyalgia story: medical authority & women's worlds of pain*. Philadelphia, PA: Temple University Press.
- Barker, K. (2008). Electronic support groups, patient-consumers, and medicalization: the case of contested illness. *Journal of Health and Social Behaviour*, 49(20), 20-36.
- Berelson, B. (1971). *Content analysis in communication research*. New York, NY: Hafner Publishing CO.
- Bernhoft, B. (2012). *Chaos Theory*. Fractal Foundation. Accessed from: <http://fractalfoundation.org/resources/what-is-chaos-theory/>

- Berry, D. M. (2004). Internet research: privacy, ethics and alienation: An Open Source Approach. *Internet Research*, 14(4), 323-332.
- Birnbaum, M. G. 2013. The front students use: Facebook and the standardization of self-presentations. *Journal of College Student Development*, 54(2), 155-171.
- Borges-Rey, E. (2015). New images on Instagram: The paradox of authenticity in hyperreal photo reportage. *Digital Journalism*, (4)1, 1-23.
- Boulos, M. N. K., Giustini, D. M., and Wheeler, S. (2016). Instagram and Whatsapp in health and healthcare: An overview. *Future Internet*, 8(37): 1-14.
- Bradshaw, T. K. (2008). The post-place community: Contributions to the debate about the definition of community. *Community Development*, 39(1): 5-16.
- Branco, J. C., Bannwarth, B., Failde, I., Abello Carbonell, J., Blotman, F., Spaeth, M., and Matucci-Cerinic, M. (2010). Prevalence of fibromyalgia: A survey in five european countries. *Seminars in Arthritis and Rheumatism*, 39(6), 448-453.
- Bruan, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2): 77-101.
- Brown, P., Lyson, M. and Jenkins, T. (2011). From diagnosis to social diagnosis. *Social Science and Medicine*, 73(1): 939-943.
- Bullingham, L., and Vasconcelos, A. C. 'The presentation of self in the online world': Goffman and the study of online identities. *Journal of Information Science*, 39(1): 101-112.
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2014, December). Tri-Council Policy Statement: Ethical conduct for research involving humans. [http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf)
- Ceko, M., Bushnell, M. C. and Gracely, R. H. (2012). Neurobiology underlying fibromyalgia symptoms. *Pain Research and Treatment*, 12: 1-12.
- Chakrabarty, S. and Zoorob, R. (2007). Fibromyalgia. *American Family Physician*, 76(2), 247-254.
- Chandler, D. (2002). *Semiotics: The basics*. New York, NY: Routledge.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Choumutare, T., Fernandez-Luque, L., Arsand, E, and Hartvigsen, G. (2011). Features of mobile diabetes applications: Review of the literature and analysis of the current applications

- compared against evidence based guidelines. *Journal of Medical Internet Research*, 13(3): 287-292.
- Creswell and Miller. (1997). Research methodologies and the doctoral process. *New Directions for Higher Education*, 99, 33-46.
- Crooks, V. A. (2007). Exploring the altered geographies and lifeworlds of women living with fibromyalgia syndrome. *Social Science and Medicine*, 64(3), 577-588.
- Crooks, V. A., Chouinard, V. and Wilton, R. D. (2008). Understanding, embracing, rejecting: women's negotiations of disability constructions and categorizations after becoming chronically ill. *Social Science and Medicine*, 67, 1837-1846.
- Danesi, M. 2004. *Messages, signs, and meanings: A basic textbook in semiotics and communication*. Toronto, ON: Canadian Scholars Press, INC.
- D'Arcy, Y., Kraus, S., Clair, A., and Kiley, D. (2016). Fibromyalgia: Timely diagnosis and treatment options. *The Nurse Practitioner*, 41(9): 37-43.
- Denzin, N. K. (1995). Information technologies, communicative acts, and the audience: Couch's legacy to communication research. *Symbolic Interaction*, 18(3), 247-268.
- European Commission (2014). *European citizens' digital health literacy*. London, England: European Union.
- Fernandez-Luque, L. and Bau, T. (2015). Health and social media: Perfect storm of information. *Healthcare Informatics Research*, 21(2): 67-73.
- Fitzcharles, M. A. and Yunus, M. B. (2011). The clinical concept of fibromyalgia as a changing paradigm in the past 20 years. *Pain and Research Treatment*, 12(1), 1-8.
- Fitzcharles, M. A., Ste-Marie, P. A. and Pereira, J. (2013). Fibromyalgia: Evolving concepts over the past 2 decades. *Canadian Medical Journal*, 185(13), 645-651.
- Garcia-Palacios, A., Herrero, R., Vizcaino, Y., Belmonte, M. A., Castialla, D., Molinari, G., Banos, R. M., and Botella, C. (2015). Integrating virtual reality with activity management for the treatment of fibromyalgia: acceptability and preliminary efficacy. *Clinical Journal of Pain*, 31(6): 564-572.
- Gaysynsky, A., Romansky-Poulin, K., and Arpadi, S. (2015). "My yap family": Analysis of a Facebook group for young adults living with HIV. *AIDS Behaviour*, 19, 947-962.
- Gerwin, R. (2013). Are peripheral pain generators important in fibromyalgia and chronic widespread pain? *Pain Medicine*, 14(6), 777-778.

- Gibbs, J. L., Ellison, N. B., and Heino, R. D. (2006). Self presentation in online personals: The role of anticipated future interaction, self-disclosure, and perceived success in internet dating. *Communication Research*, 33(2), 152-177.
- Gil, P. (2016, Oct 19). What is a meme? What are some examples? *Lifewire*. Accessed from: <https://www.lifewire.com/what-is-a-meme-2483702>
- Gil-Orr, O., Levi-Belz, Y., and Turel, O. (2015). The “Facebook-self”: Characteristics and psychological predictors of false self-presentation on Facebook. *Frontiers in Psychology*, 6, 1-10.
- Glouberman, S. (2011). Online health advice sought by more Canadians. *CBC News*. Accessed from: <http://www.cbc.ca/news/online-health-advice-sought-by-more-canadians-1.982301>
- Goffman, E. (1959). *The presentation of self in everyday life*. New York, NY: Anchor Books.
- Goffman, E. (1961). *Encounters: Two studies in the sociology of interaction*. Middlesex, England: Penguin University Books.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Toronto, ON: Simon & Shuster INC.
- Goodwin, I., Griffin, C., Lyons, A., McCreanor, T. and Barnes, H. M. (2016). Precarious popularity: Facebook drinking photos, the attention economy, and the regime of the branded self. *Social Media and Society*, 2(1): 1-13.
- Griffis, H. M., Kilaru, A. S., Werner, R. M., Asch, D. A., Hershey, J. C., Hill, S., Ha, Y. P., Sellers, A., Mahoney, K., and Merchant, R. M. (2014). Use of social media across US hospitals: Descriptive analysis of adoption and utilization. *Journal of Medical Internet Research*, 16(11): 264-273.
- Hallberg, L. R. and Carlsson, S. G. (2000). Coping with fibromyalgia. *Scandinavian Journal of Caring Sciences*, 14(1): 29-36.
- Heish, H-F. and Shannon, S. E. (2005). Three approaches to content analysis. *Qualitative Health Research*, 15(9), 1277-1288.
- Hodge, R. and Kress, G. 1988. *Social semiotics*. Ithaca, N.Y.: Cornell University Press.
- Ibrahim, Y. (2015). Instagramming life: banal imaging and the poetics of everyday life. *Journal of Media Practice*, 16(1), 42-54.
- Instagram. (2016). *Instagram stats*. Retrieved from: <http://instagram.com/press/>

- Jones, K. D., Mist, S. D., Casselberry, M. A., Ali, A., and Christopher, M. S. (2015). Fibromyalgia impact and mindfulness characteristics in 4986 people with fibromyalgia. *Explore*, 11(4): 304-309.
- Jones, R. A. (1994). The ethics of research in cyberspace. *Internet Research*, 4(3), 30-35.
- Jutul, A. (2015). Beyond the sociology of diagnosis. *Sociology Compass*, 9(9): 841-852.
- Jutul, A. and Nettleton, A. (2011). Towards a sociology of diagnosis: Reflections and opportunities. *Social Science and Medicine*, 73(6): 793-800.
- Juuso, P., Skar, L. Sundin, K., and Soderberg, S. (2016). The workplace experiences of women with fibromyalgia. *Musculoskeletal Care*, 14: 69-76.
- Karimkhani, C., Connett, J., Boyers, L., Quest, T., and Dellavalle, R. P. (2014). Dermatology on Instagram. *Dermatology Online Journal*, 20(7) 6-10.
- Kitchin, H. A. (2003). The Tri-Council policy statement and research in cyberspace: Research ethics, the internet, and revising a 'living document.' *Journal of Academic Ethics*, (1)4, 397-418.
- Knibbs, K. (2014, January 21). Instagram is growing faster than Twitter, Facebook, and Pinterest combined. *Digital Trends*. Accessed from: <http://www.digitaltrends.com/social-media/instagram-is-growing-faster-than-twitter-facebook-and-pinterest-combined-in-2013/>
- Leiss, W., Kline, S. and Jhally, S. (1997). *Social communication in advertising*. New York, NY: Routledge.
- Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Social Science & Medicine*, 57(6): 1045-1054.
- Madden, S. and Sim, J. (2006). Creating meaning in fibromyalgia syndrome. *Social Science & Medicine*, 63, 2962-2973.
- Madden, S., and Sim, J. (2016). Acquiring a diagnosis of fibromyalgia syndrome: The sociology of diagnosis. *Social Theory & Health*, 14(1): 88-108.
- Mann, C. and Stewart, F. (2000). *Internet communication and qualitative research*. Los Angeles, CA: Sage.
- Mano, R. S. (2014). Social media and online health services: A health empowerment perspective to online health information. *Computers in Human Behaviour*, 39(1), 404-412.

- Marshall, T.C., Lefringhausen, K., and Ferenczi, N. 2015. The big five, self-esteem, and narcissism as predictors of the topics people write about on Facebook status updates. *Personality and Individual Differences*, 85, 35-40.
- Miserandino, C. (2006). *The spoon theory*. Accessed from: <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>
- Munson, S., Cavusoglu, H., Frisch, L., and Fels, S. (2013). Sociotechnical challenges and progress in using social media for health. *Journal of Medical Internet Research*, 15(10), 226-235.
- Paulson, M., Danielson, E. and Soderberg, S. (2002). Struggling for a tolerable existence: The meaning of men's lived experiences of living with pain of fibromyalgia type. *Qualitative Health Research*, 12(2), 238-249.
- Pinch, T. (2010). The invisible technologies of Goffman's sociology: From the merry-go-round to the internet. *Technology and Culture*, 51(2): 409-424.
- Preece, J. and Maloney-Kirschmar, D. (2005). Online communities: Design, theory and practice. *Journal of Computer-Mediated Communication*, 10(4): 1-3.
- Rasmussen-Pennington, D. M., Richardson, G., Garinger, C., and Contursi, M. L. (2013). "I could be on Facebook by now": Insights from Canadian youth on mental health information. *Canadian Journal of Information and Library Science*, 37(3), 183-200.
- Ren, Y., Harper, F. M., Drenner, S., Terveen, L., Kiesler, S., Riedl, J., and Krut, R. E. (2012). Building member attachment in online communities: Applying theories of group identity and interpersonal bonds. *MIS Quarterly*, 36(3): 841-864.
- Ren, Y., Kraut, R., and Kiesler, S. (2007). Applying common identity and bond theory to design of online communities. *Organization Studies*, 28(3): 377-408.
- Rothblatt, M. (2011). *From transgender to transhuman*. USA: Martine Rothblatt.
- Ross, D. R. (2007). Backstage with the knowledge boy sand girls: Goffman and distributed agency in an organic online community. *Organization Studies*, 26(3): 307-325.
- Rooke, B. (2013). Four pillars of internet research ethics with web 2.0. *Journal of Academic Ethics*, 11(4), 265-268.
- Sannicolas, N. (1997). Erving Goffman, dramaturgy, and on-line relationships. *Cybersociology*. Accessed at: [http://www.cybersociology.com/files/1\\_2\\_sannicolas.html](http://www.cybersociology.com/files/1_2_sannicolas.html)
- Scott, Stanford and Thompson. (2004). Killing me softly: Myth in pharmaceutical advertising. *British Medical Journal*, 329(7480), 1484-1487.

- Skuladottir, H. and Halldorsdottir, S. (2008). Women in chronic pain: Sense of control and encounters with health professionals. *Qualitative Health Research*, 18(7), 891-901.
- Smith, R. L., and Sanderson, J. (2015). I'm going to Instagram it! An analysis of athlete self-presentation on Instagram. *Journal of Broadcasting and Electronic Media*, 59(2), 342-358.
- Soderberg, S., Lundman, B. and Norberg, A. (1999). Struggling for dignity: The meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, 9(5), 575-587.
- Statista. (2015). *Average number of Instagram followers of teenage users*. Statista. Accessed from: <https://www.statista.com/statistics/419326/us-teen-instagram-followers-number/>
- Thomas, D., Forcht, K. A., and Counts, P. (1998). Legal considerations of internet use - issues to be addressed. *Internet Research*, 8(1), 70-74.
- Toma, C. L. and Carlson, C. L. (2015). How do Facebook users believe they come across in their profiles? A meta perception approach to investigating Facebook self-presentation. *Communication Research Reports*, 32(1), 93-101.
- Tyler, L. (2012). *The Butterfly Effect*. Chronicles of Fibromyalgia. Accessed from: <http://chroniclesoffibro.blogspot.ca/2012/02/butterfly-effect.html>
- Upbin, B. (2012). Facebook buys Instagram for \$1 billion. (2012, April 9). *Forbes Magazine*. Accessed from: <http://www.forbes.com/sites/bruceupbin/2012/04/09/facebook-buys-instagram-for-1-billion-wheres-the-revenue/#53aa80d9447f>
- UVIC Human Research Ethics Board. (2013, June). Annotated Guidelines. <http://www.uvic.ca/research/assets/docs/Ethics/Annotated%20Guidelines%20HRE%20Application%20Form.pdf>
- Vincent, A., Whipple, M. O., and Rhudy, L. M. (2016). Fibromyalgia flares: A qualitative analysis. *Pain and Medicine*, 17(1): 463-468.
- Warrell, J. G. and Jacobsen, M. (2014). Internet research ethics and the policy gap for ethical practice in online research settings. *The Canadian Journal of Higher Education*, 44(1), 22-37.
- Werner, A., Isaksen, L.W., and Malterud, K. (2004). 'I am not the kind of woman who complains of everything': Illness stories on self and shame in women with chronic pain. *Social Science & Medicine*, 59, 1035-45.
- Wolfe, F. (2015). The status of fibromyalgia criteria. *Arthritis & Rheumatology*, 67(2): 330-333.

- Wolfe, F. and Hauser, W. (2011). Fibromyalgia diagnosis and diagnostic criteria. *Annals of Medicine*, 43(7), 495-502.
- Wolfe, F., Ross, K., Anderson, J., Russell, I. and Hebert, L. (1995). The prevalence and characteristics of fibromyalgia in the general-population. *Arthritis and Rheumatism*, 38(1), 19-28.
- Yan, Z., Wang, T, Chen, Y. and Zhang, H. (2016). Knowledge sharing in online health communities: A social exchange theory perspective. *Information and Management*, 53(1): 643-653.
- Zhang, Y., He, D., and Sang, Y. (2013). Facebook as a platform for health information and communication: A case study of a diabetes group. *Journal of Medical Systems*, 37(3), 1-12.

## **Appendices**

**Appendix One-** Recruitment Script for Instagram Message to Potential Interview Participants

Hello, my name is Ashley Berard and I am a Graduate student in the department of Sociology at the University of Victoria, located in British Columbia, Canada. As a Graduate student, I am required to conduct research as part of the requirements for a Master's degree. It is being conducted under the supervision of Dr. Andre Smith. The study is titled Exploring Instagram as an Online Illness Community for those living with Fibromyalgia. I am messaging you as I located some of your posts and account searching #fibromyalgia. I have selected you to interview as you have posted with this hashtag and have received high number of likes and/or comments on such posts. If you would be interested in participating in the study, I will either email you interview questions or send you the interview questions via this message, which you could complete in an email or in this message thread and send back to me. You can decide if you would rather complete this interview in this message or by email. The interview should take no longer than an hour and asks about your experience on the app. If you agree, please reply to this message stating whether you would like to conduct the interview via the app or email (if email, please include your email address) and I will send along a consent form and more information about the study. If you would like to participate in this interview, but for any reason are unable to do so via email or the app, please let me know and I can arrange a telephone interview with you. If you have any questions, please do not hesitate to ask me here. Thank you for your time.

## Appendix Two - Consent Form

### *Participant Consent Form*

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#### **Exploring Instagram as an Online Illness Community for those Living with Fibromyalgia**

You are invited to participate in a study entitled Exploring Instagram as an Online Illness Community for those living with Fibromyalgia that is being conducted by Ashley Berard under the supervision of Dr. Andre Smith.

Ashley Berard is a graduate student in the department of Sociology at the University of Victoria and you may contact her if you have further questions by email at [aberard@uvic.ca](mailto:aberard@uvic.ca).

As a Graduate student, I am required to conduct research as part of the requirements for a Master's degree in sociology. It is being conducted under the supervision of Dr. Andre Smith. You may contact my supervisor at 250-721-7583.

#### **Purpose and Objectives**

The purpose of this research project is to gain understanding of the use of Instagram as a place of community or support for those living with fibromyalgia. The study hopes to examine how individuals connect with others on the application or share about their own illness experience through the production of images and posts.

#### **Importance of this Research**

Research of this type is important because previous studies have identified that individuals living with fibromyalgia may be stigmatized or face a lack of clear understanding of their symptoms. Due to this, it is important to understand the impact this has on individuals and where individuals turn to for support or resources. Instagram is under-researched, meaning that this study will contribute to the field in terms of understanding the role social media can play in the daily routine of individuals. The study will also contribute to the overall knowledge of fibromyalgia based on subjective descriptions.

#### **Participants Selection**

You are being asked to participate in this study because you were identified as using the #fibromyalgia on some of your Instagram posts. Only participants whose accounts are set to public can be identified and contacted. Individuals were found by searching the hashtag on Instagram.

**What is involved**

If you consent to voluntarily participate in this research, your participation will include participation in an email interview. If you agree to the study and sign this consent form, once the researcher has received it, you will be sent the ten interview questions. You are able to complete these email questions on your own and send them back to the researcher when they are completed. The interview should take no longer than an hour and your answers may be as detailed as you would like.

Your interview will be analyzed by the transcript that you send back with your answers.

**Inconvenience**

Participation in this study may cause some inconvenience to you, specifically the amount of time it takes you to complete the survey.

**Risks**

There are some potential risks to you by participating in this research and they include possible emotional stress due to the nature of the questions, as the topic of your illness experience may be sensitive. To prevent or to deal with these risks the following steps will be taken; you will be able to view the questions before you decide to answer them, and if you feel the questions will be taxing on you, you may decline or withdraw from the interview process at any time. You are also able to decline to answer a specific question if you feel it is too sensitive to discuss. It is entirely up to you as to how much detail you put into your answers.

**Benefits**

The potential benefits of your participation in this research includes the benefit to you in discussing your experience. It may be beneficial to you to share about your illness experience, if you would like to help contribute to the state of knowledge of fibromyalgia and believe your lived experience can contribute to the field.

Your perspective is greatly appreciated as this study will benefit the state of knowledge and society by providing information about an illness that is frequently stigmatized or misunderstood. Further, explaining the role of Instagram or social media in your illness experience may help to provide information on a potential resource for those living with chronic illness. Further, by providing information about the possible benefits of Instagram, other support services may potentially view social media as an area to consider when providing these services.

**Compensation**

There will be no compensation for participating in this study.

**Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be removed from the study. You may choose to withdraw after receiving the interview questions and in this case, you are in no way obligated to return the questions or partial answers to the researcher. If you have submitted your responses to the researcher and choose to withdraw the researcher will remove you from the study and delete all records of your interview transcript.

**Anonymity**

In terms of protecting your anonymity your name will only be known to the researcher and after receiving your responses, you will be immediately given a pseudonym which will appear in the data analysis and possibly in the subsequent written report. Your Instagram username or real name will not be attached to the data in any form and will only be known by the researcher.

**Confidentiality**

Your confidentiality and the confidentiality of the interview transcript will be protected in password protected files which only the researcher has access to. The email and Instagram accounts which are used for communication between you and the researcher are only accessed by the researcher and are password protected.

**Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways; a written thesis, a thesis presentation, and possible conference presentations or public presentations. Electronic copies of the written thesis will be sent to you once completed.

**Disposal of Data**

Data from this study will be disposed of once the written thesis has been completed. It will be disposed of by being completely erased from the computer and email account. Messages on Instagram will also be erased. However, some quotes from the interview transcripts may be used in the written report and/or presentations.

**Contacts**

Individuals that may be contacted regarding this study include the primary researcher, Ashley Berard at [aberard@uvic.ca](mailto:aberard@uvic.ca) and supervisor, Dr. Andre Smith at [apsmith@uvic.ca](mailto:apsmith@uvic.ca) or 250-721-7583.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

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<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
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***Please keep a signed copy of this consent for your records and email another signed copy back to the researcher at [aberard@uvic.ca](mailto:aberard@uvic.ca) who will keep a copy as well.***

**Appendix Three- Interview Questions**

1. How long have you been a user of Instagram?
2. Have you been diagnosed with fibromyalgia?
3. How often do you post using the #fibromyalgia?
4. Why do you choose to post images with the #fibromyalgia? What do these images usually depict?
5. How would you describe the level of support you have, either online or offline, in your illness management?
6. Has or does your illness impact(ed) your ability to engage in activities such as work, social events, or school?
7. Have you or do you expect to connect with others who live with fibromyalgia within the app?
8. Is your followers list composed more prominently of individuals you know offline or only online?
9. Do you post about fibromyalgia on any other social media sites? If so, which ones?
10. Is there anything specific about your experience on Instagram in relation to your illness management that you would like to include?

**Appendix Four-** Interview demographics

<b>Interview Demographics</b>			
	<b>Diagnosed with Fibro</b>	<b>Amount of time on Instagram Posting about Illness (Years)</b>	<b>How often posting with #fibromyalgia</b>
Participant 1	Yes	5	Roughly three times a week
Participant 2	Yes	2	Every day
Participant 3	Yes (+ UCTD)	2	Every day
Participant 4	Can't be diagnosed	.5	Only about once every few months
Participant 5	Yes	1	Every day
Participant 6	Yes	2	Roughly three times a week
Participant 7	Can't be diagnosed	4	Every day
Participant 8	Can't be diagnosed	3.5	Roughly three times a week
Participant 9	Yes	2	Every day
Participant 10	Yes	2	Few times a month
Participant 11	Can't be diagnosed	1	Every day
Participant 12	Yes	2	Few times a month

### Appendix Five- Metrics Tables by Categories

<b>Category: The Day</b>							
	Rain/Snow	Clouds	Sun	Physical activity	In bed	Non-physical activity (movie theatre, reading)	Doctor/hospital visit
Post 1	1	1					
Post 2	1						
Post 3			1			1	
Post 4			1		1		
Post 5				1			
Post 6			1		1	1	
Post 7		1	1				
Post 8							1
Post 9						1	
Post 10						1	
<b>Total</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>1</b>	<b>2</b>	<b>4</b>	<b>1</b>

**Total posts in category: 10/50**

**% of total data set: 20%**

<b>Category: Pain</b>							
	Treatment: Medication	Treatment: Alternative (bath, hot water bottle)	Body part: Legs/feet	Body Part: Arms/Hands	Artistic photo of pain (e.g. barbed wire, rocks in body)	Online created photo describing pain	Positive experience of conquering pain
Post 11	1						
Post 12						1	
Post 13		1	1				
Post 14	1						
Post 15		1					
Post 16			1				
Post 17		1	1				
Post 18					1		
Post 19					1		
Post 20				1		1	
Post 21							1
Post 22						1	
Post 23						1	
Post 24		1		1			
Post 25						1	

Post 26						1	
Post 27		1					
Post 28						1	
Post 29						1	
<b>Total</b>	<b>2</b>	<b>5</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>8</b>	<b>1</b>

**Total posts in category: 19/50**

**% of total data set: 38%**

<b>Category: The Face</b>								
	Frown	Smile	Thumbs down	Looking away from camera	Mask	Face positioned lying down/among blankets	Face positioned towards light	Crying
Post 30	1			1				1
Post 31	1							
Post 32	1			1		1	1	
Post 33	1		1					
Post 34					1			1
Post 35	1					1		
Post 36							1	
Post 37	1							
Post 38						1		
Post 39	1					1		
Post 40		1						
Post 41		1						
Post 42					1			
Post 43	1					1		
Post 44								
<b>Total</b>	<b>8</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>2</b>	<b>5</b>	<b>2</b>	<b>2</b>

**Total posts in category: 15/50**

**% of total data set: 30%**

<b>Category: Awareness</b>					
	Fibromyalgia literature	Body part with writing on it	Television appearance	Tattoo	Written explanation of handing illness
Post 45	1				
Post 46		1			
Post 47		1			
Post 48			1		
Post 49				1	
Post 50					1
<b>Total</b>	<b>1</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>1</b>

**Total posts in category: 6/50**  
**% of total data set: 12%**

## Appendix Six- Metrics Table of Post Details

Instagram Post Demographics							
	Date Posted	Description of image	Key Phrases in Caption	Hashtag(s)	Number of "likes" on post	Number of comments on post ( <i>Tone-positive versus negative</i> )	Number of followers on user's account
<b>Post 1</b>	Feb 11/2016	Snowy road, through car window, intersection ahead with green light	-blizzard like day -disability insurance -ending claim -pre-existing condition -I feel broken	Spoonie, chronicillness, chronicpain, fibromyalgia, invisibleillness, blizzard2016, heartbroken	212	50 Sympathetic, empathic, support, understanding	4937
<b>Post 2</b>	Feb 1/2016	Pill boxes, pills, bed	-this is getting out of hand	Spoonie, chronicillness, chronicpain, fibromyalgia, invisibleillness	330	48 Advice, Support, questions	4937
<b>Post 3</b>	September 24/2015	Book on fibro fog/illness, scientific proof fibro is real, in bed, blankets, pen for notes with yellow paper	-some good reading today	Spoonie, chronicillness, chronicpain, fibromyalgia, invisibleillness	100	20 Discussion on book, statements regarding legitimacy of fibro	4937
<b>Post 4</b>	Feb 16/2016	Black and white computer image, mans face surrounded by symptoms including anxiety, CFS, IBS, Fibro, depression	-so many things connected -don't take personally when healthy people give you advice -they don't understand -had a very exciting weekend but	Spoonie, IBS, butyou dont look sick, kidney disease, hope, fibromyalgia, lupus, chrons, cfs, California, Chicago, committed	135	15 Discussion of others not understanding illness, advice on symptom management	5831

			body isn't catching up -relearning body after trip -hopeful for new lifestyle regimen -sending you all love				
<b>Post 5</b>	Feb 1/2016	Computer image, CFS and Fibro, misdiagnosis of fibro is actually lyme, get right diagnosis and you can heal	All hashtags	Spoonie, chronicillness, chronicpain, fibromyalgia, invisibleillness, butyou dont look sick, autoimmune disease, ra, spoontheory, fms, migrains, epsteinbarr	53	12 Discussion on lyme disease versus fibro	3240
<b>Post 6</b>	Feb 22/2016	Bath tub, red toes, bubbles, dark	-insomnia palace -feeling like I never want to get out	Bubblebath, epsomsalt, chronicpain, chronicallyill, fibromyalgia, rheumatoid disease, toes, prettytoes, spoonie, spoonielife, painmanagement	35	1 Nothing like a warm bubble bath	1076
<b>Post 7</b>	Feb 17/2016	Pill container with many different pills on pink counter	-when I used to think of having cocktails when I grew up, this isn't what I imagined	chronicpain, chronicallyill, fibromyalgia, rheumatoid disease, toes, prettytoes, spoonie, spoonielife, painmanagement, cocktail, prescriptions, ovariancyst	39	4 Frustration with medicine	1076

<b>Post 8</b>	Oct 26/2015	Thumb with heart drawn onto the nail with pen – black and white	-love yourself, inside and out. forget about your flaws and remember that you can be completely and utterly you	chronicpain, chronicallyill , fibromyalgia	10	0	1076
<b>Post 9</b>	Oct 25/2015	Five selfies- all crying/despair, close up some black and white	-starting photo series about living with chronic pain -includes pain, doctors visits, foods, hospitals -going through neuralgia flare -after it was under control, you can see I was still in agony	chronicpain, chronicallyill , fibromyalgia, rheumatoiddisease, toes, prettytoes, spoonie, spoonielife, painmanagment, fibromyalgia sucks, spooniesunit e, arthritis, arthritissucks , miserable	34	8 Relating to images, support, thanks for putting face to pain, explaining own situations	1076
<b>Post 10</b>	Feb 21/2016	Rainy window, drops on window, very grey and dark blurry objects behind glass	-mini rant alert -half term hasn't been as bad compared to most weeks -stress, anxiety, fatigue are playing huge part in pain levels and all are extremely high at school -the one thing I really hate is you can't see it	Fibrofighter, fibromyalgia, chronicfatigue, chronicillness, anxiety, pain, myfoggydays , depression, invisibleillness, cold, chronicallym e, photography, bedbound	64	5 – understanding, hugs, support	876

			-people judge you for being lazy or being rude				
<b>Post 11</b>	Feb 11/2016	Hot water bottle on knees in jeans, probably in living room space at home, rug and couch	-it's so cold, I'm having a flare up	Fibrofighter, fibromyalgia, chronicfatigue, chronicillness, anxiety, pain, myfoggydays, depression, invisibleillness, cold, chronicallyme, photography, bedbound, insomnia, spoonieneeds help, anxiety	61	7 – support and love	876
<b>Post 12</b>	Jan 9/2016	Mirror selfie, hair up, grey sweater, blue jeans, small smile	-putting on a brave face but everything hurts so much, does anyone have suggestions for what painkillers/meds to go on	Fibrofighter, fibromyalgia, chronicfatigue, chronicillness, anxiety, pain, myfoggydays, depression, invisibleillness, cold, chronicallyme, photography, bedbound, insomnia, spoonieneeds help, anxiety, pain, helpme, vsco, blogger, nomotivation	35	16- discussion of different pain meds, compliments, types and amounts of medication	876
<b>Post 13</b>	Nov 6/2015	Palm of hand with pen writing on it that says “I have fibromyalgia. If my pain	-1- read about fibro -2-post palm that says I have fibro or I know	Fibromyalgia palmchallenge, fibromyalgia	60	1 – wow I am impressed, feeling empowered. thank you for	1046

		was visible my whole body would be black and blue”	someone with fibro -3-tag photo with hashtag -spoonie version of icebucket and it is desperately needed for research/awareness			the inspiration	
<b>Post 14</b>	June 30/2015	Beach, sunny day, blue sky and water	-today was incredibly challenging fibromyalgia day -the heat doesn't agree with me -had one of those rare I can't deal with the heat and pain days -when I got home was tempted to just go to bed -but decided to go to beach instead	Fibromyalgia , beach, britishheatwave, spoonie, butyou dont look sick, bloggers, sunshine	38	8 – wow you are strong, good for you, so positive, sending love, support	1046
<b>Post 15</b>	April 14/2015	Picture of inflamed leg with red spots all over, black background, sitting down	-oh hello random inflammation of my knee and leg that radiates heat, I have NOT missed you	Fibromyalgia , spoonie, invisible illnesses, inflammation	13	1 – sending spoons	166
<b>Post 16</b>	Feb 24/2016	Picture of legs under the covers in bed, with open notebook beside, window on wall curtains	-meant to be revising but feels like I've been hit by a train -head sore, nausea, pain everywhere, and no energy	Fibromyalgia , spoonie, invisible illnesses, stress	7	1- stay strong, you can do this, fibro always hits me hardest at the worst times too (#fellowspoonie)	166

		open and sunny	-thanks ibs and fibro just what I needed when revising				
<b>Post 17</b>	Feb 25/2016	Selfie, resting on bed/couch, bright sunlight, sad face, looking away from camera	-hooked up to TENS unit, topical pain relief patch applied and heatpack too -I cried this morning just because I'm so sad I'm losing all the progress I made and I just feel rotten -I have a phone consultation with doctor on Monday and I need to arrange an assessment of my asthma -Tuesday I'm just spending it out with my mum and sister and may pop out in a bit for some air -my stomach is ridiculously painful and bloated and my limbs feel like they are going to fall off and I have a migraine -apart from that I'm	Myfabulouslife, fibromyalgia, pots, chronicillness, ME, gastroparesis, symptomssuck, chronicpain, angry, annoyed, sad, defeated	47	3- heart, take it easy, it's hard when you have been feeling great for days then get knocked down	737

			absolutely fine ☺				
<b>Post 18</b>	Jan 12/2016	Bare legs outside on blanket, sunlight, tattoo on ankle	- fibromyalgia legs are tired! Didn't get to have my nanna nap today -I feel like death -also quit my job because my doctor, my friends and I all don't think it is safe for me to be working when I am having collapses every day	Spoonie, chronicillness, chronicpain, chronicnausea, invisibleillness, fibromyalgia, gastroparesis	36	9-hugs, sending you spoons, wish you best, take care	466
<b>Post 19</b>	Feb 19/2016	Selfie, painted nails, thumbs down, sad face	-today is awful, paying badly for last two days at work -Had hoped I wouldn't have to take a tramadol this week but it is too severe today, so I'm having to give in -this pain is just too much	Fightlikeagirl, fibromyalgia, endo, endopain, invisibleillness, chronicallyill, chronicpain, chronicillness, badpainday, endometriosis	43	9- sending love, support, understanding, stay strong, no idea how you do it	801
<b>Post 20</b>	October 21/2015	Drawn image, girl crying while taking mask off, close up, black and white	-Today has been a really tough day. Pain has been so bad and I barely slept last night because of it	Fightlikeagirl, fibromyalgia, endo, endopain, invisibleillness, chronicallyill, chronicpain, chronicillness	54	17- understanding, sorry you have to go through this, sending you a huge hug, I feel you honey, it's hard trying to	801

			<p>-Tired to explain to a colleague but she said 'I guess we just have to live with these things'</p> <p>-People don't understand and don't appreciate how hard getting through a day with a debilitating illness is. I kept my public brave face on as I do all day at work</p>	s, badpainday, endometriosis, spoonie, spoinelife, pain, flare, endosister		explain to others, you're one of the strongest ladies I know	
<b>Post 21</b>	Feb 7/2016	Girl doing archery, with other woman standing beside her	-Came in second in the ladies! Def something I would want to continue	Fibromyalgia , spoonie, archery, bowandarrows	28	1- love archery	386
<b>Post 22</b>	Aug 22/2015	Selfie, in bed all white sheets and wall, looks tired	<p>-Really struggled to get up this morning. But I made it into work.</p> <p>-Everything is hurting, especially my ribs and my hands</p>	Chronicillness, cfs, spoonie, chronicfatigue, chronicpain, invisibleillness, LA, pain, fibromyalgia	28	0	386
<b>Post 23</b>	Feb 25/2016	Bed, white with sheets, plaid pillow and laptop opened, she is clearly working in the ed	-signing the papers to drop out of uni and restart next year due to being too unwell to continue -not sure what to do	Chronicillness, cfs, spoonie, chronicfatigue, chronicpain, invisibleillness, pain, fibromyalgia, butyou dontlo	23	2- such a shame, that is awful you had to make that decision	386

			about living accomodatio sns now or money -I will work it out though, it's the best thing for me at the moment	oksick, uni, university			
<b>Post 24</b>	Feb 24/2016	Computer image, girl wrapped up in barbed wire, heavy black make up, messy hair, no clothing, brown and black tone photo	All hashtags	Fibro, fibrowarrior, fibrofighter, fibromyalgia, stayingstrong , stayingpositi ve, smile, smilemore	14	0	129
<b>Post 25</b>	Feb 11/2016	Human made of wire (like a statue type thing), filled with rocks, on concrete outside (possible store) window, small rose in right hand corner	All hashtags	Braininjury, ptsd, fibromyalgia, wounds, RSD, austismaware ness	16	0	506
<b>Post 26</b>	Jan 15/2016	Computer image, man's back, bruised body, veins, writing on image states that if fibro was visible this is what it would look like	-bad days look like this but I keep going so a bad day doesn't turn into a bad week or bad year	Fibromyalgia , fibro, keepfighting, strong, fibrofit, fitness, beatfibromya lgia, fibrowarrior	5	0	103
<b>Post 27</b>	Jan 24/2016	Woman on top of cliff/peak, blue sky,	-Killing my fibromyalgia with every step	Fibromyalgia , fibro, keepfighting, strong,	32	0	470

		hands on hips		fibrofit, fitness, beatfibromyalgia, fit, fibrowarrior, countryside, countingspoons, keeppushing, cfs			
<b>Post 28</b>	Sept 10/2015	Selfie, woman by window, looking strong, a bit blurry, blue tones	-Everyday holds great potential- ASK RECEIVE BELIEVE -Living strong and living well – despite my fibro- it does not define me	Fibromyalgia , fibro, countingspoons, cfs, faith, gypsy, fighter,	20	1- !!!!!	470
<b>Post 29</b>	July 20/2015	On set interview	-Had a great interview today with nick coit of abc6wine in Providence Rhode Island along with my sister. -Tune in to watch segments of our interview discussion our fight against fibromyalgia	Fibromyalgia , destined4destinee, champscamp	594	1 – so proud	42.2K
<b>Post 30</b>	Deeshumway – sad selfie	Selfie- sad face, a little blurred, standing	-how I'm feeling today	Fibromyalgia , selfie, me, fibrofighter, fibromyalgia sucks, backpainsucks, backpain	23	3- smily faces, you're cute even in pain	252
<b>Post 31</b>	Jan 22/2016	Computer image- animated girl	-You'll have to forgive my lack of food	Fibromyalgia , fibro, countingspoon	26	2- hope you start feeling better soon, I	252

		in pink dress with eyes down, looking tired. Blue butterfly beside her. Writing says "Unless you have to rest after a shower, you have no idea what fatigue is"	pics and interesting stuff. -I'm kinda having a huge flare up -I hope you're all having a much better week than me	ns, cfs, chronic illnesses, invisible illness, invisible pain, chronic fatigue syndrome, spoonie life, spoonie, exhaustion, fibromyalgia sucks		have been here many times, hearts	
<b>Post 32</b>		Woman sleeping, probably on couch, mouth open, brown sheets/pillow, dark photo	-so my amazing husband took this photo so when I questioned why I was on the couch in the morning he could show me I was out cold -I always tell him if I'm passed out on the couch don't wake me up to bring me to bed because I can't sleep again	Classic beauty, best husband, fibromyalgia, fibro hurts, fibro fatigue, out cold, sleeping like a boss	7	2-out like a light	218
<b>Post 33</b>	Feb 16/2016	Selife, making a frustrated face, sitting up on couch	-Pain! There is only so much a person can take before it starts to wear them down -I am tired of getting the run around. I was diagnosed with	Fibromyalgia, exhausted, ow, fibro sucks, awareness, chronic pain, in need answers, fibro sucks	5	5- questions about pain management, conversation with advice on management	181

			<p>fibromyalgia in 2010  -I have lost my career path as a personal trainer and more and more I feel like I am losing myself.  -I will never get too far gone. I have my sweet loves to be strong for!</p>				
<b>Post 34</b>	Buttonsword86	Selfie (collage of three pictures) in a black sweater, smiling, holding up sweater to show stomach in one of the images	<p>-Okay so left I am showing off my new sweater  -to the right is my swollen stomach which is hidden by the baggy jumper  -stomach usually swells due to ibs and eds  gastrointestinal issues and its pretty painful but I continue to smile  -there have been so many questions as to why I wear baggy tops and its days like these</p>	365daysofchronicillness, day2, fibromyalgia, eds, ibs, depression, anxiety, nofilter, chronicillnesses, chronicfatigue	30	1 – thanks for posting about ibs, we wish more people would talk about this common issue!	219
<b>Post 35</b>	Feb 10/2016	Grey sky day, clouds	-Do you see the light?	Hospital, pain,	32	5-conversation-	755

		with small sliver of light sky over city landscape	-Always remember the storm will end and you will see the sun again -Yesterday was stormy for me. Pain was high and there were no answers -Today I can see the sun again. I still have pain, but it's a lot more bearable -And it seems like I am getting more answers. They will do more specific tests tomorrow and hopefully I will get a diagnosis.	diagnosis, rare disease, invisible illness, spoonie, spoonie needs help, chronic illnesses, chronic pain, sun, bloodwork, doctors, fibromyalgia, nature photography, from the window, diagnose, positivity		thinking of you today, raining today so pain is up, thinking sunny	
<b>Post 36</b>	March 2/2016	Selfie- Three women, the poster is the youngest, mom and grandmother hugging in background	3 generations of spoonies	Blogger, fibromyalgia, spoonie, spoonie blogger, joint hypermobility syndrome, family	12	3- gorgeous picture	43
<b>Post 37</b>	Jan 13/2016	Computer image – cracked face, skin is edited to look as though it is cracked, eyes down, dark hair	-repost, only because lupus/behcets /fibro/ra has been and will always be a part of my life -I was scared to see my rheumatologist	Lupus, RA, fibromyalgia, stress, spoonie, sick, feeling better,	53	12- congrats, happy for you	884

			<p>st but instead  I got a big hug saying I was in remission  -to make these difficult life altering challenges was killing me in so many ways  -when you see the differences these changes have made its eye-opening  -stress is a killer  -being in an unhappy relationship was drowning me  -it's been over a year since a severe flare  -I've had many small flares that I could still function with</p>				
<b>Post 38</b>	July 7/2015	Tattooed foot- purple ribbon with zipper on edges	<p>-Just had my chiari tattoo done  -everyone loves it and so do I</p>	Chiari, tattoo, chronic, chiarian, chiarigirl, chiarisurvivor, fibro, fibromyalgia	27	1- I love that my mom and I got matching ones	608
<b>Post 39</b>	Feb 26/2016	Computer image- blue background, woman's body that looks as though	<p>-Absolutely. This is what's happening right now. There are lightning</p>	Spoonie, spoonielife, fibromyalgia, cfs, chronic illnesses, invisibleillness	34	3- or bug bites! hornet bites maybe	818

		yellow and red electricity is running through Text on image says: Fibromyalgia pain sometimes feels like little zaps of electricity	bolts under my skin. And it's amazing something so painful can't be seen. It hurts SO bad -Goodnight guys. I hope everyone is okay tonight	ss, invisiblepain, chronicfatigu esyndrome, spoonielife, spoonie, exhaustion, fibromyalgia sucks, nonceliacglut ensensitivity, mecfs, bpd, vertigo, fibroflare,, fibrowarrior			
<b>Post 40</b>	Feb 24/2016	Hand in (compression ) glove, painted nails on red surface	My hands are so swollen!! And painful. my fingers look like sausages ☹ it's been a long day. a nap is needed	Spoonie, spoonielife, fibromyalgia, cfs, chronicillnes s, invisibleillne ss, invisiblepain, chronicfatigu esyndrome, spoonielife, spoonie, exhaustion, fibromyalgia sucks, nonceliacglut ensensitivity, mecfs, bpd, vertigo, fibroflare,, fibrowarrior, compression gloves, imak	25	3- suggestions for a cream to help hand, natural vitamin shop recommenda tion	818
<b>Post 41</b>	Jan 26/2016	Picture of hand and wrist with a hospital band	-Getting too used to this -The nurse who drew my blood stuck me, then missed and started to fish for the vein	Spoonie, spoonielife, fibromyalgia, cfs, chronicillnes s, invisibleillne ss, invisiblepain, chronicfatigu esyndrome, spoonielife,	35	3- ouch, I've had that happen before, it hurts! Eek ☹	818

			-I HATE when they do that -I was like “I’d rather you stick me again than fish for it!”	spoonie, exhaustion, fibromyalgia sucks, nonceliacglutensensitivity, mecfs, bpd, vertigo, fibroflare,, fibrowarrior, gallbladder, fms			
<b>Post 42</b>	Feb 6/2016	Selfie – lying down, glasses, headphones in, on red pillow	-I feel unwell -ice packs, popsicles, and applesauce today -and a nap, too	Sign, Spoonie, spoonielife, fibromyalgia, cfs, chronicillness, invisibleillness, invisiblepain, chronicfatiguesyndrome, spoonielife, spoonie, exhaustion, fibromyalgia sucks, nonceliacglutensensitivity, mecfs, bpd, vertigo, fibroflare,, fibrowarrior, tired, headache, selfie, peripheralneropathy, dysautonomia	34	4- careful with all that sugar, feel better, what’s bothering me more is gluten, yes that pesky gluten	818
<b>Post 43</b>	Feb 29/2016	Computer image of snoopy on aqua background. Snoopy looks beat up, tongue out, exhausted.	-Every day....all day....	Fibromyalgia, myalgicencephalomyelitis, chronicpain, chronicillness,	41	8- this is me right now, got to copy this, sad faces, discussion on symptoms and similarities/c	1051

		Text around him says: my skin itches; what I look like and feel like every morning with fibromyalgia; my brain won't wake up; my energy is gone; my hair hurts; my muscles are stiff; my body throbs		chronicfatigue		ommonalities between those commenting and original user	
<b>Post 44</b>	March 1/2016	Picture in movie theatre, just screen and running shoes and feet up on seat in front, dark around screen	-Tonight I decided to risk my good pain day by going to the movies to see how to be single -let me just say it was definitely worth the migraine at the end	Chronicmigraines, chronicheadache, chronicillnesses, chronicpain, invisibleillness, iamnotmyillness, fibro, fibromyalgia, cinema, howtobesingle, movie, girlsnight	25	4- love that film, not one of my favourite movies, best of the day	93
<b>Post 45</b>	Feb 26/2016	Meme- cat, text says "Doctor appointment tomorrow- need to prepare notes so I don't forget my symptoms"	-multiple "ology" appointments this week	Lifeofaspoonie, spoonie, spoonieproblems, chronicillnesses, sjogrenssyndrome, fibromyalgia, chronicasepticmeningitis	32	3- good luck with appointment, the accuracy is too real	123
<b>Post 46</b>	Feb 8/2016	Picture of pink armchair in house with lamp to the side, pillow	-Feeling free today- day 3 of good days and I've come to visit my amazing grandparents	Cfs, chronicfatiguesyndrome, cfsme, invisibleillness, cfsrecovery,	60	6- hold tight, I hear the struggle, fantastic bet they loved seeing you, seeing people	793

		in armchair, dark room	-although they don't understand my illness and the way that it has made me feel, they have been there for me every step of the way. -whether it's their catch up on phone class or the food goodie bags, they've always been there	spoonie, chronicillness, onedayatim e, nevergiveup, heal, healing, sickness, health, survive, fighting, fibromyalgia, groundhogda y, endlesspain, chronicfamil y		you love is such a boost isn't it? bless them	
<b>Post 47</b>	March 3/2016	Black and white, sitting on floor of shower wrapped up in towel or house coat, wet hair	A hot bath a day keeps the doctor away	Cfs, chronicfatigu esyndrome, cfsme, invisibleillne ss, cfsrecovery, spoonie, chronicillnes s, onedayatim e, nevergiveup, heal, healing, sickness, health, survive, fighting, fibromyalgia, endlesspain, chronicfamil y, bestrong, spooner, spoons, sleeping, nap, party, sickly, sleepy, tgif, chronicallyfa bulous,	13	5- hearts, agreed!	143

				positivevibes , fibrosisters,			
<b>Post 48</b>	Feb 2/2016	Computer image of google screen where the words “fibromyalgia is” have been typed and the suggestions say “bullshit, fake, real, not real, a real disease, a fake disease, a made up disease, a label, a joke”	-me as a fibro woman, I know people don’t understand this, I don’t judge if they think it is a joke but also I’m free to declare that they are not my favourite people	Cfs, chronicfatigu esyndrome, cfsme, invisibleillne ss, cfsrecovery, spoonie, chronicillnes s, onedayatatim e, nevergiveup, heal, healing, sickness, health, survive, fighting, fibromyalgia, endlesspain, chronicfamil y, bestrong, spooner, spoons, sleeping, nap, party, sickly, sleepy, gif, chronicallyfa bulous, positivevibes , fibrosisters,	24	0	143
<b>Post 49</b>	Feb 2/2016	Computer image of a black background with a picture of a person sitting on the floor back against a wall with a window and light coming through (black and white). text at the top says	A heart and hashtags	Cfs, chronicfatigu esyndrome, cfsme, invisibleillne ss, cfsrecovery, spoonie, chronicillnes s, onedayatatim e, nevergiveup, heal, healing, sickness, health, survive,	23	1 – three hearts	143

		“Fibromyalgia is not just a word, it is a life sentence”		fighting, fibromyalgia, endless pain, chronic family, be strong, spooner, spoons, sleeping, nap, party, sickly, sleepy, tgif, chronically fabulous, positive vibes, fibrosisters,			
<b>Post 50</b>	Feb 2/2016	Selfie, lying in bed with covers over most of face, just forehead and hair showing	-You know what would be awesome, if I could just wake up one of these mornings without any pain -Name's stay in bed right now	Chronic pain, fibrofighter, trying hard, support is key, autoimmune, invisible illness, namastay in bed	1	1- totally understand, take it easy and make a cup of tea #fibrofriends	53