

#Fibromyalgia:

A Qualitative Analysis of How Males and Females Share Their Stories on Instagram

Ela Sakotic

MacEwan University

BCSC 203: Major Research Paper

Instructor: Marlene Wurfel

December 3rd, 2020

(3,971 words)

Abstract

Fibromyalgia (FM) is a chronic illness that affects millions of people worldwide. Despite some people referring to FM as a woman's disease, men also suffer from the illness. This study asks how males and females use Instagram to communicate about their illness and discusses how themes differ throughout their narratives. A qualitative research approach was taken to conduct a narrative analysis and look at images for their connotative meaning. This study indicates that females share their narratives on Instagram at a higher frequency than males. Thematic analyses suggest that both males and females use Instagram to share pain narratives and lend one another support. While most of the themes were the same, the findings indicate that females are more likely than males to share their struggles with the Instagram community.

Introduction

As of 2018, more than 1 million Canadians have been diagnosed with fibromyalgia (FM) (My Health Alberta, 2018). Although many people consider FM to be a woman's disease, researchers have found that men also suffer from the illness. Data suggests that globally, between 2.40% and 4.80% of men are living with FM (Heidari et al. as cited in Muraleetharan et al., 2018, p. 952) and that 38% of American FM patients are male (Wier et al. as cited in Karper, 2007, p. 278).

FM is a chronic pain syndrome in which there is prolonged and widespread pain in all four quadrants of the body with at least 11 tender points overall (Wallace and Wallace, 2014, p. 9). Because FM is a syndrome, many symptoms can be present simultaneously (My Health Alberta, 2018). These symptoms can include pain, fatigue, insomnia, problems with memory or concentration (often referred to as "fibro-fog"), and muscle spasms (My Health Alberta, 2018; Wallace and Wallace, 2014, p. xiv). In my experience, this pain is not the typical type of pain someone experiences when they stub their toe or fall down the stairs. The pain of FM can make a shirt feel too heavy to wear, it can make hair brushing against one's back feel like razor blades, or being touched by a cold hand feel like getting stabbed.

FM can make the most simple of tasks feel like torture. Individuals with FM may struggle to get out of bed in the morning and take time off work or school to cope with their symptoms. They also face the challenge of those around them being unable to understand the condition (Paxam, 2019, p. 3). For this reason, I wanted to answer the following research questions: what are the recurring themes in communications from individuals with FM? How do these themes differ between males and females? To answer these questions, I completed a narrative analysis of

the images and captions used in a selection of posts on Instagram then looked at the connotative meaning behind each post.

Literature Review

Individuals with FM often feel stigmatized and isolated because they must repeatedly prove the legitimacy of their condition to both the medical and the non-medical communities (Dymon, 2015, p. 7 as cited in Berard & Smith, 2019, p. 238; Paxman, 2019, p.3; Sendra & Farré, 2020, p. 46). My Health Alberta (2018) recommends that those with FM consider “seeing a psychologist specializing in pain treatment.” A psychologist can help individuals with FM cope with the effects of their illness, such as loneliness and shame, pain flare-ups, and the significant challenges faced in their personal and professional lives (My Health Alberta, 2018; Paxam, 2019, p.1; Sendra & Farré, 2020, p. 46). However, not everyone has the means or the opportunity to see a psychologist.

As discussed by researchers such as Paxam (2019), some people choose to share their stories through online communities (pp. 4-5). Berard and Smith (2019) and Ressler et al. (2012) indicate that belonging to a supportive community that allows people to discuss their illness may help them cope with FM (p. 238; p. e143). Individuals with FM and other chronic illnesses have taken their narratives to social media as a way to express themselves and get a level of support that is not readily available offline (Berard & Smith, 2019, p. 241; Sendra & Farré, 2020, pp. 47-52). Berard and Smith (2019) found that Instagram also plays a role in creating awareness about FM as some users indicate that the people around them do not understand what it is like to deal with FM symptoms (pp. 244-245).

While there is plenty of research on FM in general, there is a disproportionate amount of research that looks at how males cope with FM. When Berard and Smith (2019) and Paxam (2019) assessed individuals' narratives of FM, they looked at the data as a whole rather than comparing the narratives of male users to the narratives of female users. The result of this is that female narratives get studied more often than male narratives. Muraleetharan et al. (2018) conducted research to learn about FM's impact on men, and their results were similar to Paxam's (2019) research, which predominantly looked at female narratives. Muraleetharan et al. (2018) revealed that many men experience a negative impact on their quality of life, relationships with family and friends, and struggle to maintain their gender roles (pp. 954-955). Many other narratives expressed by the male participants in Muraleetharan et al.'s (2018) research echoed the narratives of the female participants in the research conducted by Berard and Smith (2019), Paxam (2019), and Senda and Farré (2020).

There is a lack of understanding of how and if males and females use social media differently when discussing FM. Previous literature that studied both sexes suggests that similarities exist, but a direct comparison of the narratives is necessary to discover how they may differ. Revealing the differences will allow those with FM to receive better support and care from their healthcare practitioners, family and friends, and workplaces by bringing awareness to their different needs.

Research Method

A qualitative research method was used to gather rich data on the different communication strategies of males and females with FM on Instagram. With guidance from Groenewald (2004) and Lester (1999), I took a phenomenological approach to illuminate the

experiences of those with FM. As Lester (1999) said, “phenomenology is concerned with the study of experience from the perspective of the individual” (p. 1), which makes it the ideal approach to understand how people with FM feel about and experience their illness.

Sendra and Farré’s (2020) method of categorizing the Instagram posts they analyzed inspired the categorization used in this research study (p. 48). Specifically, Table 3 of Sendra and Farré’s (2020) research provided the categories for visual representations and photographic frames listed in Table 1 of this study (p.48). Other elements shown in the tables of this study are a result of narrative analysis. I used Ignatow and Mihalcea’s (2017) narrative analysis method to investigate the meaning behind the text posts and captions of the selected Instagram posts (pp. 90-93). “Narrative analysis focuses on the ways people make and use stories to interpret the world” (Ignatow & Mihalcea, 2017, p. 90). The texts were analyzed using both functionalist and sociological narrative approaches. “Functionalist analysis of narrative[s]...focuses on what particular stories *do* in the contexts of people’s everyday lives,” as the narratives often deal with “solving problems, reducing tension, and resolving dilemmas” (Ignatow & Mihalcea, 2017, p. 91). Regarding the sociological approach, Ignatow and Mihalcea said that the focus is “on the cultural, historical, and political contexts in which particular stories are, or can be, told by particular narrators to particular audiences” (p. 92). The contexts of the sociological approach are relevant because FM is an invisible illness, and users often strive to legitimize their condition to others (Paxman, 2019, p.3).

Method of Data Collection

I chose to analyze posts from Instagram because Instagram allows users to express themselves through images, videos, and words using a single application. Instagram is a popular

social media application that many individuals with chronic illnesses use to bring social awareness to their illness (Paige et al., 2017 p. 266). Also, Instagram is where I found a supportive community when I was first diagnosed with FM.

Posts were collected from October 23-25, 2020. I intended to collect posts by searching the hashtag #fibromyalgia and selecting five accounts run by males and five accounts run by females. Males and females were determined by apparent sex, based on their profile photo and other photos on their Instagram page. Sex, rather than gender, was used because an Instagram search does not have the option to filter by gender, nor does every Instagram user state their gender in the biography section of their profile. As this was research limited to non-human subjects (Instagram posts rather than Instagram users), it was not appropriate to contact Instagram users to verify their gender identity.

To be selected for the sample, each account had to meet the following criteria: (a) have at least ten posts about FM; (b) be publicly visible (in other words, no private accounts were eligible); and (c) posts must not be commercial. Then, ten recent FM related posts from each account were selected for a total sample of 100 posts. There were over 1.8 million posts tagged with the hashtag #fibromyalgia at the time of data collection. The majority of the posts viewed in the search were from female users, and none of the viewed accounts that featured males fit the sample criteria. In order to find accounts run by males, the search was expanded to include the hashtag #menwithfibromyalgia, which had fewer than 4,000 posts at the time of data collection. Most of the males who used the hashtag #menwithfibromyalgia also used the hashtag #fibromyalgia on their posts. However, because of the volume of posts tagged with the hashtag #fibromyalgia, accounts run by males were not seen during the original search.

Due to the limited number of male users who posted about FM, the first five male-run accounts that met the sample criteria were selected for analysis of male users. Since female users were abundant, I chose five that seemed interesting based on their content. These were users that I, as an individual with FM, could relate with.

Data Analysis

The 100 selected posts were saved on Instagram using the save feature. Then a narrative analysis was done for each post to organize the content thematically. Posts were categorized as positive, negative, or neutral. They were also categorized by whether they had a caption. Positive posts were ones that seemed hopeful, helpful, or supportive. These posts may have also been about the user having a good day or looking for the positive in a negative situation. Posts that were cynical, angry, or sad were listed as negative. Other posts that fell into the negative category focused predominantly on pain narratives or feelings of defeat. Some captions fit into both the positive and negative categories as some users shared their pain narratives and the bad days they experienced as well as a hopeful message of better days to come. Strictly fact-based posts were coded as neutral.

Images were categorized based on their visual representations and framing (Table 1). Instagram has a carousel feature that allows users to post up to ten images in a single post. Some posts used this feature, which resulted in a total of 111 images from 100 posts. A few users also posted photo collages. When looking at the photographic frames for the images, each image in a photo collage was assessed individually, which resulted in 120 images.

To categorize the images according to their themes, they were analyzed using Roland Barthes' concept of denotative and connotative meaning, which "describe different kinds and

levels of meaning produced at the same time” (Sturken & Cartwright, 2018, p.29). The denotative meaning of an image is “its literal, explicit meaning,” whereas the connotative meaning is “informed by the cultural and historical contexts of the image and its viewers’ lived, felt knowledge of those circumstances—all that the image means to them personally and socially” (Sturken & Cartwright, 2018, p. 29). The connotative approach of analyzing images combined with a narrative analysis allowed me to look deeper into each post’s meaning to determine the message each poster was trying to send.

Table 1*Visual Representations and Framing of Posts*

Categories	Male	Female	Total	Percentage
<u><i>Visual Representations in posts</i></u>				
Photo	17	22	39	35.1
Digital image (text image, mème, digital art)	32	32	64	57.7
Video	3	1	4	3.6
Photo collage	2	1	3	2.7
Boomerang	1	0	1	0.9
<u><i>Photographic frames (all images)</i></u>				
Face	7	1	8	6.7
Hands	6	0	6	5
Half – full body	6	17	23	19.2
Other (pets, nature, other people, food/beverage)	11	8	19	15.8
Text only	24	15	39	32.5
Cartoon/meme	8	17	25	20.8

Discussion

The first question of this study asks what the recurring themes in communications from individuals with FM are. Seven common themes were derived through deep narrative and photographic analysis. Themes were coded as (1) pain narratives; (2) support for others; (3) no energy or low energy; (4) users struggling with their illness; (5) user explains FM or brings awareness to the illness; (6) user discusses other chronic illness(es); and (7) managing symptoms (Table 2). From the 100 posts analyzed, pain narratives were the most common theme overall. This finding indicates that these individuals use Instagram as a platform where they can freely talk about their illness without worrying about being stigmatized. As one user said in a post, “I am trying to be grateful of [*sic*] the life I have but I made this account to complain about my pain so here we go, if you don’t want to read just keep scrolling!” (N A T, 2020). The idea that some

Table 2

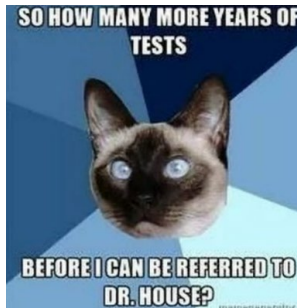
Narrative Themes

Themes	Male	Female	Total
<u>Overall themes</u>			
Positive outlook	26	17	43
Negative outlook	22	28	50
Neutral/factual	6	5	11
Uses words FM related words (fibromyalgia, fibro-fog, etc.)	20	12	32
No caption	10	20	30
Mentions doctor	7	10	17
<u>Specific themes</u>			
Pain narratives	15	17	32
Support for others	10	13	23
No energy or low energy	9	5	14
Struggling with illness	9	20	29
Explains condition/ awareness	9	7	16
Other chronic illness	8	3	11
Managing symptoms	2	10	12

users created their Instagram accounts to vent about their illness may explain why half of the posts can be classified as having a negative outlook (Table 1). The second most common narrative was users lending support to others by ending captions with messages such as “DMS [direct messages] always open if someone need [sic] a friendly non judgemental ear!” (Some Guy with Fibro, 2020). Many users ended their captions in a similar way, which suggests that even if they chose Instagram as a platform to vent about FM, they are also interested in connecting with others in the FM community.

It is interesting to note that most users did not use the term fibromyalgia or other related terms such as fibro-fog in their posts. While they all used the hashtag #fibromyalgia, only 32 posts used FM related words. Most users chose to refer to FM as their illness, which may be partly because some users have other chronic illnesses as well. Some of the other illnesses discussed by users, such as chronic fatigue, functional bowel disorder, and headaches, are associated with FM (Wallace & Wallace, 2014, Table 13.6, p. 111). Users who used FM-related words did so to describe issues others may not understand, such as fibro-fog or FM pain. One text post read, “I haven’t been drinking it’s the effect of Fibromyalgia and you never know when or how it will strike” (Rockell, 2020).

Of the 100 posts analyzed, 17 mentioned doctors. Of those 17 posts, 14 had a negative perspective on their relationship with their doctor; the other three were categorized as neutral. The users expressed frustration that doctors do not understand enough about FM. Some said that their doctors do not believe that their pain is as bad as they say. ChronicallyME said that doctors could be invalidating and discriminatory (2020). Three separate users posted some version of an image in which a doctor tells them not to confuse their Google search with the doctor’s six years of medical school. In the image, the patient responds by telling a doctor not to confuse their one-

Figure 1*Doctor House Meme*

(Heather, 2020)

hour lecture with the patient's years of experience with the illness (Juggy, 2020; mrs h p, 2020; Fibromyalgia Fitness Coach, 2020). Other users used sardonic humour to represent their frustration with their doctors.

When looking at the image framing, the majority (69.1%) of the photos were of something other than the individual. Most (57.7%) of the images were some form of a digital image such as a meme or text-only image. It is possible the users who avoid posting photographs of themselves feel more comfortable with the anonymity of a digital image. Another possibility is that these digital images can better express the way users feel. Since FM is an invisible disease, these digital images are likely more representative of how a user feels than any photograph of their face or body would be.

The second research question asks how the themes represented in the posts differed between males and females. The visual representations between males and females were very similar as both used the same number of digital images throughout their posts and nearly the same number of photographs. Even the photographic frames were nearly the same, with females being in their photos 31% of the time and males being in their photos 30.6% of the time.

Figure 2*Fibromyalgia Patient Disguised as a Healthy Person*

(Robledo, 2020)

To better answer the question, I looked at the connotative meaning of each image and caption. Males had more positive posts (26%) than female users (17%), but the frequency of negative themes was more similar, with 22% of male posts and 28% of female posts expressing negative themes. Some posts were coded as having both positive and negative themes if content expressed pain narratives or cynicism along with a hopeful message and support for others. There were also twice as many posts by females than males that did not have a caption. Likely, users felt that the images they posted could tell their story just as well as or better than any caption could. The most glaring difference between themes among male and female users was struggling with the illness. Whereas only 9 posts by male users discussed the struggle they experienced in dealing with FM, there were 20 posts made by female users. N A T wrote:

Of course the pain comes on the weekend. I was looking forward to this weekend. I wanted to get a lot of stuff done. I had small things planned that I wanted to get done, all

paced out, super spoonie friendly. But now, I will most likely end up curled up in bed. The jobs will get put off for another day, I'll be left feeling unaccomplished. I'm frustrated because this has been me for the last week. My motivation is super low because my pain is super high. I'm frustrated because each night I go to bed hopefully [*sic*] that tomorrow will be different, but at the moment it all feels like groundhog day and I'm over it. (2020)

A spoonie is someone who uses the spoon theory to “represent the limited stores of energy [one is] forced to exert with every little chore and social interaction” (Hess, 2016). A post about struggling with FM from the male perspective said, “my chronic health problems have taken so much from me but I'm still here...just not the way I'd like” (Juggy, 2020).

The only other theme that had a difference of more than five posts was pain management. Females discussed pain management ten times, whereas males only mentioned it twice. A post from Fibromyalgia Fitness Coach described how she has to exercise to manage the pain of FM:

I HAVE to workout [*sic*] because I have Fibromyalgia. When I studied exercise and Fibromyalgia for my Masters degree, a lot of my research focused on starting a workout habit...what the research hasn't shown is what happens when someone with Fibromyalgia stops working out. Does the pain come back? Personally, I've found that yes it does. (2020)

One male also posted about the importance of exercise to manage his pain. Rockell shared, “It takes some effort but I know that my #fibromyalgia is much worse if I don't get out for my daily #exercise” (2020).

Figure 3

Word Cloud From Female Users' Captions



Figure 4

Word Cloud From Male Users' Captions



This study indicates that both males and females are more interested in creating a supportive community than educating others about FM. Since multiple users discussed their struggle to legitimize their condition, I expected more posts that described the illness. In this study, only 16 posts focused on educating others about FM. A final point concerns how the majority of users who post with the hashtag #fibromyalgia are female. The lack of male users suggests that males may prefer to use other platforms to discuss their illness or are not comfortable sharing their narratives online.

Conclusion & Further Research

This study agrees with Berard and Smith's (2019) findings that Instagram is a platform where "users can share knowledge and support one another" (p. 245). However, when looking for samples, the search results indicate that females share their narratives on Instagram at a much higher frequency than males. The most common themes among the posts studied were pain narratives and support for others. While most themes appear with similar frequency from male and female users, female users were more likely to share the hardships of having FM. Muraleetharan et al. (2018) state that "health-related impacts can be more significant in men" (p. 956), yet this study indicates that the experiences are quite similar. This finding does not come as a surprise since Muraleetharan et al.'s (2018) research on men showed the same themes as described by researchers such as Paxam (2019), whose research was conducted predominantly on women. Further research is required to determine whether there is a difference in how males and females experience FM.

There were several limitations to this study. First, as "Instagram is more popular among female Internet users" (Berard & Smith, 2019, p. 239), it was difficult to find male users for the

study. Looking at other social media platforms, such as Reddit and Twitter, may provide more in-depth information. Also, ten Instagram users are not representative of the millions of individuals who have FM. Further research should use a larger sample to get more generalizable results. With proper ethics board approval, further research should also include interviews or surveys to allow individuals to share their stories in the context of the research questions. Finally, age and gender demographics may impact the results. Since Instagram users do not always indicate age or gender, future research on FM patients should consider demographics to determine whether themes change when non-binary individuals are included and compare results from different age groups. By studying more narratives from FM patients, researchers and healthcare professionals can better determine these individuals' needs and find more ways to support them.

References

- Berard, A. A., & Smith, A. P. (2019). Post your journey: Instagram as a support community for people with fibromyalgia. *Qualitative Health Research*, 29(2), 237-247.
<https://doi.org/10.1177/1049732318789102>
- Groenewald, T. (2004). A Phenomenological Research Design Illustrated. *International Journal of Qualitative Methods*, 42–55. <https://doi.org/10.1177/160940690400300104>
- Heather, V. [@vin.heat]. (2020, September 24). #mengetfibromyalgiatoo #menwithfibromyalgia #migraine #fibromyalgia #fatigue #fibroflare #fibrofog #anxiety #autoimmunedisease #chronicpain #chronicfatiguesyndrome #chronicdisease #invisibleillness #insomnia #neuropathy #pain #sensoryoverload [Meme]. Instagram.
<https://www.instagram.com/p/CFg-6q5DmEl/>
- Hess, A. (2016, March 4). *The social media culture: How people with chronic illnesses use memes, selfies, and emojis to soothe their suffering*. Slate.
<https://slate.com/technology/2016/03/how-spoonies-people-with-chronic-illnesses-use-memes-selfies-and-emojis-to-soothe-their-suffering.html>
- Ignatow, G., & Mihalcea, R. (2017). *Text mining*. SAGE Publications.
<https://dx.doi.org/10.4135/9781483399782.n8>
- Karper, W. B. (2007). Exercise effects on two men with fibromyalgia syndrome. *American Journal of Men's Health*, 1(4), 278-283. DOI: 10.1177/1557988307300469
- Lester, S. (1999). *An introduction to phenomenological research*. Stan Lester Developments, Taunton.
https://www.researchgate.net/publication/255647619_An_introduction_to_phenomenological_research

- P., M., H. [@fibromrsp]. (2020, October 18). #fibromyalgia #fibromyalgiasucks #fibromyalgiaawareness #fibro #fibromyalgiawarrior #fibromyalgiamom #fibromyalgiasupport #fibromyalgiafighter #fibromyalgiasymptoms #chronicfatiguesyndrome #chronicfatigue #chronicillness #chronicillnessawareness [Digital image]. Instagram. <https://www.instagram.com/p/CGe37T1BdyC/>
- Muraleetharan, D., Fadich, A., Stephenson, C., & Garney, W. (2018). Understanding the impact of fibromyalgia on men: Findings from a nationwide survey. *American Journal of Men's Health*, 12(4), 952–960. <https://doi.org/10.1177/1557988317753242>
- My Health Alberta. (2018, May 10). *Living with fibromyalgia*. My Health Alberta. <https://myhealth.alberta.ca/Alberta/Pages/living-with-fibromyalgia.aspx>
- Paxman, C. G. (2019). “Everyone thinks I am just lazy”: Legitimacy narratives of Americans suffering from fibromyalgia. *Health*. <https://doi.org/10.1177/1363459319857457>
- Ressler, P. K., Bradshaw, Y. S., Gualtieri, L., Chui, K. K. H. (2012). Communicating the experience of chronic pain and illness through blogging. *J Med Internet Res*, 14(5), e:143 [10.2196/jmir.2002](https://doi.org/10.2196/jmir.2002)
- Robledo, A. V. [@beibevega]. (2020, November 3). *Repost @fibromyalgia_girl #ImStillME #fighter #fibrosucks #fibrowarrior #recovery #survivor #searchME #stayathome #spoonie #fightlikeagirl #loveluna #celeryjuice #fibromyalgia #remission* [Digital image]. Instagram. <https://www.instagram.com/p/CHIXLxYDFAS/>
- Paige, S. R., Stellefson, M., Chaney, B. H., Chaney, D. J., Alber, J. M., Chappell, C., & Barry, A. E. (2017). Examining the relationship between online social capital and eHealth literacy: Implications for Instagram use for chronic disease prevention among college students. *American Journal of Health Education*, (48)4, 264-277. <https://doi.org/10.1080/19325037.2017.1316693>

Sendra, A., & Farré, J. (2020). Communicating the experience of chronic pain through social media: Patients' narrative practices on Instagram. *Journal of Communication in*

Healthcare, 13(1), 46-54. <https://doi.org/10.1080/17538068.2020.1752982>

Sturken, M., & Cartwright, L. (2018). *Practices of looking: An introduction to visual culture* (3rd ed.). Oxford University Press.

Wallace, D. J., & Wallace, J. B. (2014). *Making sense of fibromyalgia: New and updated* (2nd ed.). Oxford University Press.