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VISUALIZING INVISIBLE CHRONIC PAIN

An Analysis of YouTube-Based Multimodal Illness Narratives

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Degree of Master of Science in Medical Anthropology*

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ABSTRACT

Social media has become ubiquitous in recent decades, and researchers across disciplines have investigated the use of social media in medical contexts amongst patients and practitioners (Craig 2015, Heathcote et al. 2018). Medical anthropologists have argued that consideration of patient illness narratives is essential to fully understanding illness experiences and providing adequate care (Edmond & Keefe 2015, Kleinman 1988, Mattingly 1998). YouTube has become a platform for individuals to craft and broadcast their illness narratives, and its use is notably salient amongst those with invisible chronic pain. This exploratory study focuses on 72 YouTube videos self-published by 12 distinct users with chronic pain. Through a digital ethnographic approach, the video-blogs, ‘vlogs’, are analyzed as multimodal illness narratives.

By bringing into dialogue preexisting ethnographic studies and digital YouTube illness narratives this paper investigates the unique capabilities of visual social media as a means for sharing personal accounts of chronic pain. This study contends that chronic pain vloggers make use of the multimodal nature of YouTube to argue that their pain is real through making their chronic, invisible experiences visible. These findings illustrate the need for medical discourses to value a broader range of narratives especially when studying and treating illnesses like chronic pain that cannot be visualized or measured using standard biomedical methods.

Keywords: chronic pain, invisible illness, multimodality, illness narratives, social media, patient advocacy, health communication.

INTRODUCTION

Sufferers of invisible illnesses, particularly chronic pain, report facing alienation from their social worlds, and the medical community, and consequently struggle to have their pain understood and believed (Good 1992, Naslund et al. 2014, Serlin 2010). The inability to communicate invisible pain further isolates sufferers, making their illnesses debilitating (Charon 2008, Scarry 1987). Increasingly, chronic pain sufferers have been turning to social media, and YouTube in particular, to share their illness narratives (Gonzalez-Polledo & Tarr 2016, Melander 2019). This study proposes that the multimodal nature of YouTube provides individuals with chronic pain an outlet to make their experiences visible and, in doing so, demonstrate that their invisible pain is ‘real’. By juxtaposing stories about not feeling seen, and not being believed, with visual ‘evidence’ of their illnesses, chronic pain vloggers are able to make meaning and find purpose out of their pain.

Forty-five percent of the United States population reports experiencing pain lasting more than six months (Jackson 2011: 370). As opposed to acute pain that can be measured by observable tissue damage, chronic pain poses more of a threat to the credibility and definitiveness of biomedicine as it is incurable and commonly impossible to diagnose biologically (Honkasalo 2001: 320). Acute pain is seen as serving a biological function and indicates either nociceptive or neurogenic damage. Chronic pain, in comparison, often cannot be traced to tissue damage and thus is not believed to have a biological function. Sufferers who are un-

able to receive the support and solutions they need from the medical world, turn to other outlets to address the physical and psychosocial symptoms of their pain (Naslund et al. 2014). While biomedical research in chronic pain is still insufficient, social scientists have shepherded research into the multifaceted phenomenon of chronic pain and the complex biopsychosocial impacts it has on sufferers (Craig 2015, Honkasalo 2001, Kelley & Clifford 1997).

In recent years, scholars across disciplines have turned to social media as a means to study the ways individuals and communities utilize the internet to address their health concerns (Craig 2015, Heathcote et al. 2018). Some anthropologists have also explored internet-based illness narratives as a way to address topics such as the biosociality of virtual support networks surrounding diagnoses (Bicquelet 2017, Gibbon & Novas 2007, Huh et al. 2014, Ressler et al 2012, Wehling 2011), the therapeutic benefits of sharing illness experiences via social media (Kugelmann et al. 2019, Page 2013), and the value of multimodal storytelling for those coping with illness (Luzzatto et al. 2003, Lynch et al. 2013, Melander 2019). While some studies have looked specifically at the use of YouTube amongst the chronic pain community (Bicquelet 2017, Forgeron et al. 2019), research lacks on why the multimodal nature of YouTube videos makes the platform particularly valuable to those whose pain is invisible and challenging to communicate.

The phenomenon that social media provides a space for connecting and creating communities around health and illness is acknowledged, and is generally unsurprising (Fox 2020, Huh et al. 2014, Page 2013); Social media is intrinsically social (Naslund

et al. 2014, Serlin 2010, Heathcote et al. 2018). The question remains: why YouTube? What is beneficial, appealing, or practical about broadcasting intimate, at times self-exposing, videos about one's illness experiences? As Broderick Fox further inquires, 'why would someone point the camera onto their pain and then choose to share it with a public, often emboldened by the Web's anonymity to produce lazy language and hate speech?' (2020: 251). In other words, individuals with chronic pain – who are repeatedly isolated and alienated by outsiders who do

1.1 Multimodality

Multimodality is a theory that refers to the undeniable presence of multiple modes, or semiotic systems, within a story or discourse (Cartwright & Crowder 2017, Kress & Van Leeuwen 2001, Page 2013). Social semioticians argue that it is necessary to acknowledge the existence and value of multiple literacies and methods when creating meaning (Doloughan 2011). As Cartwright & Crowder contend, 'multimodal practices enable us to transition from verbal, linear narratives and interrogations to multilinear depictions and analysis' (2017: 518). Multimodality can allow for more accessible, engaging communication and the production of more holistic 'knowledge' (Benson 2017: 2). YouTube is a notably multimodal platform, consisting of inextricable video, audio, and textual elements.

1.2 YouTube

YouTube originated in 2005 with the slogan 'Broadcast Yourself' (Vonderau & Snickars 2009: 44). From its inception, YouTube has branded itself as a participatory opportunity for every-day consumers to contribute to modern media culture. YouTube is the third most utilized digital platform, behind only Facebook and Google (Naslund et al. 2014: 2). The free, consumer-driven website has revolutionized social media, making production and dissemination of video-based media immeasurably more accessible. Vonderau & Snickars describe video-blogging or 'vlogging' as 'fundamental to YouTube's sense of community' in how the format merges the intimacy of face-to-face communication and reality television premise that the mundane can serve as entertainment (2009: 47). While digital media does have great potential for quantitative analysis, this paper draws instead from narrative-based data (Bicquelet 2017, Jewitt 2012). Rather than statistical analysis, this essay employs an anthropologically-informed perspective to emphasize the value of considering individual embodied experiences when constructing or addressing the dominant discourse of chronic pain.

not believe their pain is real – are drawn to posting on YouTube despite risks of negative reactions. This essay argues that it is the multimodality of YouTube 'vlogs' (video blogs) that allows individuals to articulate the multidimensionality of their embodied experiences. Vloggers, afforded by video's presumed authority, show their experiences to contend that their chronic pain is 'real'. YouTube can thus also serve as a creative outlet and a platform for disseminating tangible products that others can view. In this way, YouTube can be instrumental for individuals trying to make meaning out of life with chronic pain.

METHODS

While many studies have looked to social media as an opportunity for data mining (Bicquelet 2017, Jewitt 2012), fewer studies have used social media content as qualitative data. This study interprets YouTube users' self-produced videos as illness narratives, wherein 'vloggers' share their own stories about living with chronic pain.

2.1 Selection Criteria

In order to identify chronic pain vloggers for analysis, I ran an initial query of 'my chronic pain' through YouTube's search engine. The inclusion of 'my' intended to separate videos created by individuals about their own pain experiences from those published by third-party organizations or medical professionals. This also ensured that only individuals who had self-identified as having chronic pain were included. The initial search yielded 21,500 videos. From here, I reviewed results in order of 'relevance' as determined by YouTube's algorithm following the below criteria:

1. *The YouTube channel contains at least three videos primarily about chronic pain, (i.e. not pain that is secondary to another chronic illness).*
 2. *The pain videos are self-published by the chronic pain sufferer.*
 3. *The channel is not advertising or selling a product or treatment plan.*
 4. *The videos are in English.*
1. *More than 50% of published videos are specifically about chronic pain.*
 2. *The user's three most popular videos are about chronic pain.*
 3. *The user has been posting videos on YouTube for at least a year and has posted a video about chronic pain within the last year.*

Once data saturation was reached (Saunders et al. 2017, Glaser & Strauss 2017) and further examination of search results circled back to channels already included, 58 channels by individual YouTubers with chronic pain remained. This preliminary exploratory investigation was used to observe general themes regarding the use of YouTube to share information about personal chronic pain experiences. Appendix A provides basic demographic data from the large sample. Age, gender, and pain type were easily accessed for the majority of YouTubers; identifying characteristics were either directly listed in the users' 'About' page or articulated directly within the videos. Information regarding identifiers such as race and geographic location were not always available, and were thus excluded from the demographics tables to avoid making assumptions about how individuals self-identified.

In order to conduct a more in-depth, ethnographic analysis using the videos as illness narratives, a smaller subset of channels was selected from the preliminary sample. The following criteria were employed to select the final collection of YouTubers.

Through the final round of selections, twelve individual channels were identified; demographic data of the final sample can be viewed in *Appendix B*. These specific criteria were applied to narrow down the scope to include only individuals who used YouTube predominantly to discuss chronic pain, and whose prolonged engagement with the platform reflected the chronicity of their condition. Because this study intends to assess the motivation behind individuals posting videos on YouTube rather than those who use YouTube only to view videos, subscriber and view counts were not used as criteria for inclusion (Gonzalez-Polledo & Tarr 2016, Naslund et al. 2014). I was also inclined to include currently active YouTubers as indication that the creators still want their videos to be in the public domain and to be viewable. At the time of writing, all videos referenced in this study were in the public domain, though may have since been removed. The creators of the videos are quoted using the aliases under which they published the video. All quotes from the videos are transcribed and punctuation and formatting reflects my closest interpretation of the vlogger's tone and emphasis.

For each channel, the top six most popular videos about chronic pain were viewed. Regardless, despite incomplete statistical data, it is still evident that the vast majority of videos are posted by young, white women. Men represented only 7% of the larger sample and after the second round of selections, all remaining channels were by women. Of the final selection, 75% of the selected vloggers were under age 40.

2.2 Limitations

The intention of this study is to address 'why' individuals are using YouTube, rather than 'who' is using YouTube to speak about pain. While beyond the scope of this paper, the topic of representation and diversity amongst chronic pain vloggers is critical and undoubtedly warrants further research. This essay further argues that multimodal illness narratives on YouTube contribute to the creation of a language for pain, but, while this language may be more accessible and inclusive, it is not universal (Gonzalez-Polledo & Tarr 2016: 16). The most obvious limitation to this analysis is that only videos by English-speakers were included. As pain expressions and communication strategies vary substantially between languages, this is a direction for further research that would likely be particularly compelling.

Naomi Sunderland references the 'excluded voice thesis' that argues that narratives, and especially multimodal narratives, are quintessential to the holistic and authentic representation of oppressed groups (2015: 53). While many of the vloggers in this study seem to be turning to YouTube in response to feeling unheard and marginalized, there are many still who remain excluded from the narrative. There are many who lack access to technological means or who do not feel as though they can speak publicly about their bodies and emotions (Benson 2017, Jewitt 2012, Molyneaux et al. 2008). The age and gender breakdown of chronic pain vloggers is largely unsurprising. Young adults are

the most frequent online video viewers (Madden 2007) thus it is understandable that younger people who already spend more time on YouTube would also post videos more frequently than other age groups. Additionally, studies show that women report chronic pain up to three times more often than men, but are simultaneously more frequently told their pain is 'imaginary' or of psycho-emotional origin (Skuladottir & Halldorsdottir 2008: 894). Furthermore, in most Western cultures there are expectations about who is allowed to express pain without being labelled as 'weak' or 'vulnerable' (Fox 2020: 249; Molyneaux et al. 2008: 3). Ruth Page emphasizes how these expectations manifest on social media stating, 'women tend to be drawn to platforms and conversations focused on providing social support, men tend to focus on discussing treatment information and share less personal information/experiences' (2013: 26). Men whose pain is less often dismissed as

'imaginary' may not feel the same desire to prove that their pain is real.

Chronic pain is a complex embodied phenomenon; Elaine Scarry illustrates the disconnect that complicates the sociality of pain explaining, 'two people can be in a room together, the one in pain, the other either partially or wholly unaware of the first person's pain' (1985: 6). The inability of understanding a world that is all-encompassing to the affected individual, leads chronic pain sufferers to report feeling distanced from their immediate family members and close friends (Good 1992, Jackson 2005). The emotional experience of isolation intensifies due to stigma and sociocultural expectations surrounding pain and the public expressions of pain (Bass & Halligan 2007: 83). As evinced in this sample, YouTubers with chronic pain not only turn to the medium to connect with others with similar diagnoses, but also to pronounce multimodally the reality of their pain to those on the outside.

THE PAIN OF INVISIBILITY

Social scientists and philosophers have long been fascinated by the concept of the invisible, and particularly, the capacity of the invisible to reveal truth. Maurice Merleau-Ponty advocates for the necessary role of the invisible as a component of perception (1968, 1982). The basis of knowing, according to Merleau-Ponty, lies in the absence of knowing; objects are made visible only when their invisible aspects are recognized and addressed. He argues that it is necessary to contemplate what cannot be seen in order to rationalize with perception (1968: 151). Suhr contends with Merleau-Ponty's description of the invisible; adducing the dynamic of invisibility and social interaction, he states, 'when looking at one another, we quickly find ourselves in the realm of the invisible. Something is occurring within you as we face each other' (Suhr 2019: 30). Whereas social science has embraced the value of invisibility, the

Telling stories is a critical aspect of the human experience

biomedical world generally deems the invisible as a problem needing solution. Padfield contends, 'in an age where we increasingly rely on technology to make the body transparent and thus legible, we have become less tolerant of that which is opaque and invisible' (Padfield 2011: 245). Medical imaging devices and testing mechanisms aim to make the human body transparent, making the formerly invisible happenings within the body, visible to doctors and scientists (Craig 2015, Van Dijck 2011).

The dominant narrative surrounding chronic pain has been disproportionately shaped by those in positions of biomedical authority who often cannot relate to the embodied sensation of chronic pain (Hay 2010, Honkasalo 2001, Scarry 1985). Vlogger 'Annie Elaine' explains, 'a lot of the struggles with visibility that I face right now, particularly within my family and friends is that my type of disability is not a disability that they are used to' (2016c, 03:25-03:41). It is understandable that

chronic pain vloggers may turn to YouTube in reaction to feeling doubted and unheard due to the invisibility and lack of representation of their experiences in the dominant discourse (Kuglemaun et al. 2019: 294). The invisibility of pain is central to its debilitating capacity. Newton et al. posit, 'the invisibility of pain is possibly the central problem that sufferers face, and it is this aspect of pain that affects the identity of individuals (2013:10). When individuals with pain cannot provide visible or measurable evidence of their suffering their integrity and authenticity is questioned (Newton et al. 2013:10).

Sharing illness narratives on the internet is not merely a response to the new technological advancements of social media. Telling stories is a critical aspect of the human experience that allows for the formation of communities and empathy development (Doloughan 2011: 1). Pain expressions across species are understood to be adaptive qualities predicated by the necessity of communication, and social support, and care-taking behaviors for human survival (Craig 2015: 27). Pain is a physical but also psychosocial phenomenon. When pain is invisible and, consequently ignored, sufferers lose connections to the outside world (Hay 2010). The creators of these videos position their truth in the balance of what can and cannot be seen. They bring attention to visible elements of their experiences to highlight not only what can be seen but to remind the viewer that there is always a story that remains invisible.

THE NEXUS OF 'SEEING' AND 'BELIEVING': AFFORDANCES OF MULTIMODALITY

The argument that chronic pain sufferers post videos discussing their illness experiences to claim or prove their pain 'real' is grounded in the prevailing dogma that 'seeing is believing' (Kress and Van Leeuwen 2001). Certainly there is fallacy in the assumption that anything filmed or photographed is objective or 'truthful', but the multimodal nature of YouTube affords posters legitimacy because they are able to resist the accusation that pain is unreal due to its invisibility. YouTubers embrace the multimodal capabilities of the platform to make their experiences seen but, in doing this, simultaneously conform to the dominant narrative that pain must be visualizable in order to be biomedically legitimate.

Sociocultural understandings of film as a medium offer certain affordances in regards to the 'believability' of a narrative (Kress & Van Leeuwen 2000: 158; Melander 2019). Visual narratives do exist purely to illustrate or substantiate an existing written text. Kress refers to the 'bodily-ness' of mode; in the same way that different bodily senses offer insight to distinct aspects of an experience's 'truth,' so too do modes of communication (Kress 2003: 33). Ultimately, no matter how multimodal or multi-sensory a perspective, it cannot be claimed as an absolute truth (Kress and Van Leeuwen 2000, Sunderland et al. 2015). Multimodality elucidates the existence of multiple perspectives

and entry-points into a discourse. Suhr describes film's value to visual anthropology stating, 'the constant flow of images, sounds, and words in film parallels the way humans experience reality more closely than any other medium of communication' (2019: 44). Through embracing video's perceived 'proximity to truth' (Kress 2003: 24), illness narratives on YouTube draw attention to the multi-sensoriality of pain experiences (Doloughan 2011: 66; Jewitt 2012: 6). Underberg and Zorn contribute that, 'ethnography is both process and product, and that culture itself is about more than being or thinking; it is also a matter of feeling and sensory engagement' (2013: 18). By incorporating more diverse forms of meaning-making into narratives about health and illness, a more holistic and multidimensional, though inherently still incomplete, discourse can be developed (Ravelli & Van Leeuwen 2018: 291).

It would be naive to claim that YouTube-based illness narratives reflect the 'truth' of chronic pain solely because of their visual nature. Any attempts to articulate the dynamic interplay between occurrences within and outside of the body will inherently comprise of fictional and factual components (Cartwright & Crowder 2017: 2). As Ravelli & Van Leeuwen state, 'modality is not about what is or is not real, it is about what is represented as (and what we see as) real and it recognizes that a variety of

reality criteria exist' (2018: 294). The value of illness narratives is not solely that they hold diagnostic potential in medical spheres, but also that they emphasize the plurality of embodied experiences (Gonzalez-Polledo & Tarr 2016: 12). Solely because video has the potential to reveal truths, it does not imply that everything filmed reflects reality (Jewitt 2012: 3). It is imperative to consider the processes of translation and transposition that pain vloggers are engaging with because they highlight the way chronic pain sufferers are identifying and addressing gaps in the understanding, and thus treatment, of their conditions. While vloggers undeniably embrace the mindset that 'seeing-is-believing' in their vlogs, the emphasis on making pain visible can be interpreted as an example of Foucauldian biopower (Foucault [1975] 2003). Vloggers internalize the entrenched dominant narrative that only measurable, visible, symptoms are 'real' according to biomedicine and respond through efforts to make their pain seen. In this sense, while explicitly resisting biomedical chronic pain discourses, vloggers are implicitly reaffirming the biomedical provision that only visible symptoms are 'real'.

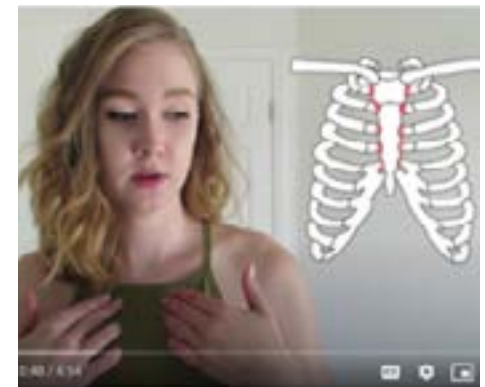
THE MULTIMODAL LANGUAGE OF PAIN

Elaine Scarry elucidated the world of pain positing, 'physical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned' (1985: 4). The physical reality of pain is unequivocal and yet attempts to quantify pain lead to ambiguity and uncertainty. Though sounds of pain may be recognizable, most languages lack vocabulary to articulate the embodied sensation of pain. The absence of sufficient language to quantify and qualify pain makes diagnosis near impossible and it can be challenging to determine when acute pain becomes chronic (Honkasalo 2001).

Vloggers are able to use YouTube to create a new multimodal language to share their illness narratives and translate the occurrences inside the body to the outer world. YouTube-based illness narratives can be particularly valuable as data because they are more accessible than biomedical research. Pain vlogs are self-published and narratives are not filtered through a doctor's lens (Bicquelet 2017: 323). The medium allows for greater diversity and representation

of voices through the propagation, and more comprehensive valuation, of multiple modes of communication (Page 2013: 16).

In the analyzed vlogs, chronic pain sufferers made use of the distinct affordances of YouTube to engage viewers through multisensory stories about their pain. The most common modal conjunctions were the visual use of gesture interposed with oral narration. Vlogger, 'Penny Brand' describes the severity of her pain stating, 'my head feels like it's about to explode. It's all around the front and then all around the back as well. It feels like it's behind my eyes' (2016c, 03:05-03:12). The vlogger is able to partner linguistic descriptors of her pain while simultaneously using her hands to gesture, showing the physicality and location of her pain. 'Live Hope Lupus' uses additional visual tools to show viewers exactly where she is feeling chest pain. While gesturing towards her own sternum, the vlogger has imposed an anatomical illustration of a ribcage with red marks notating the pain locations. Reminiscent of the biomedical desire to make visible through scanning technology like x-rays, 'Live Hope Lupus's' inclusion of the scientific rendering helps establish that the invisible occurrences within her body are observable. Through featuring the impersonal, biomedical depiction of pain alongside her own emotional narration and physical touch of her pain spots, the vlogger draws a connection between the biomedically recognized 'real' representations of pain and the personal embodied 'invisible' representations of pain.



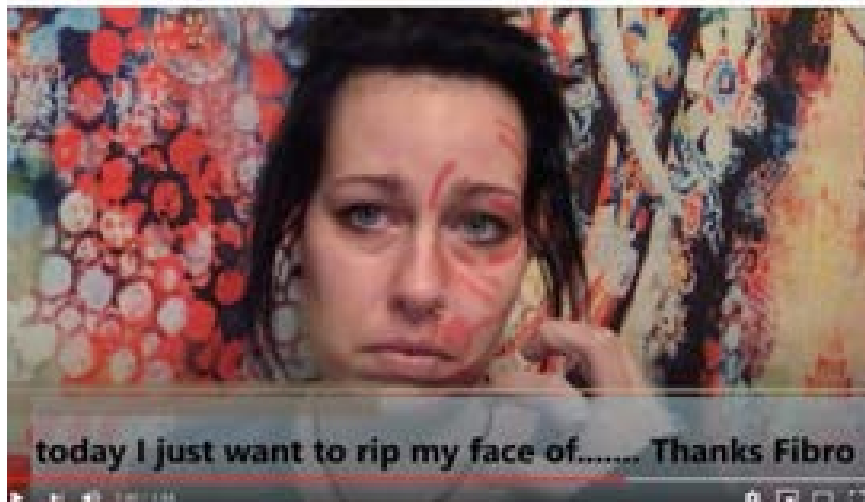
Above: 'Penny Brand' gestures while describing pain in her head (2016c: 03:10).

Below: 'Live Hope Lupus' uses an illustration of a ribcage while explaining her chest pain (2017b: 00:48).

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Recording themselves speaking about pain directly to a camera, in front of an imagined, intended, audience, allows vloggers to practice describing and expressing their pain narratives (Brokerhof et al. 2020: 1). Byron Good describes the process of interviewing someone in pain by comparing it to ‘witnessing the birth of language’ (1992: 30). Many vloggers post contextually very similar videos repeatedly. They may post ‘updates’ or ‘rants’ that focus on similar symptoms, or social frustrations or already shared anecdotes (Gonzalez-Polledo & Tarr 2016: 10). However, in each video they are able to articulate their pain in a slightly different way, using new analogies or metaphors, including visual cues or props, or showing a distinct aspect of their daily life with pain (Melander 2019: 68). The inability to articulate a physical sensation as primal as pain can lead individuals to feel like they are living in a world that is unknowable to those outside it. In response, vloggers are creating a language with which to bridge their isolated experiences with the outside world.

Rita Charon pronounced the fundamentality of narrative in medicine stating, ‘without these narrative acts, the patient cannot himself or herself grasp what the events of illness mean. The patient might not know what needs to be told’ (2008: 66). Sharing stories of pain through video-based narratives serves a practical function by enabling creators to piece together a new multimodal language. Not only are vloggers sharing insight with the public by broadcasting their stories, they are also creating meaning within themselves aiding their resilience and the development of coping mechanisms (Brokerhof et al. 2020: 1; Stainton et al. 2019: 726). The following sections focus on specific tropes and patterns surrounding the theme of pain visibility and authenticity that emerged from the selected vlogs.



Above: ‘Fibro Warrior’ uses text and red lipstick to depict her pain (2018a: 02:40)

Below: ‘Izzy Kornblau’ paints her body with make-up indicating pain caused by Ehlers-Danlos syndrome (2019c: 05:02)

5.1 Depicting Pain In & On the Body

In some instances, chronic pain vloggers consciously and tactfully embraced the visuality of the medium to illustrate what their pain looks like. Several YouTubers posted videos painting or drawing on their skin as a means to show viewers what their pain would look like if it was inscribed visibly on their bodies. ‘Fibro Warrior’ uses a tube of red lipstick to demarcate the areas of her face experiencing pain during a fibromyalgia flare-up. She does not speak but uses textual captions imposed over the video. She stares directly into the camera with a somber expression and gestures like she is clawing her face and the caption reads, “today I just want to rip my face of [sic]... Thanks Fibro’ (2018a: 02:40). The combination of text, facial expression, and red lipstick, captures the intensity of the vlogger’s pain in a way that transcends traditional bounds of symptom articulation. Similarly, ‘Izzy Kornblau’ uses powdered make-up to show where she feels pain due to Ehlers-Danlos Syndrome. While outlining shapes over her body, she narrates, describing the intensity and characteristics of each pain point. At the end, the vlogger sits in front of the camera, her whole body now in view and riddled with red splotches,. She concludes in the voice-over, ‘I think one of the most important things to take away is if you see me, I look healthy. You wouldn’t know that I experienced pain in all of these different places’ (2019c, 05:24-05:33).

Anthropologist Christian Suhr articulates the power of visual tools to reveal invisible worlds saying, ‘drawing a map brings colours and lines to unknown territories – rendering visible to the human eye a formerly impossible world of perception’ (2019: 41). Like cartogra-

phers, these YouTubers are actively embracing multimodality to bridge the gap between the inside and outside worlds of pain merging text, audio, and images. Vloggers can capture the dynamism of embodied pain experiences through video, to show how their physical state is constantly in flux; viewers are able to watch the vlogger transform in front of the camera from someone who appears to be physically ‘normal’ to someone covered with painted scars.

5.2 Being Sick while Looking Healthy

Through visual illness narratives, chronic pain sufferers draw attention to how the invisibility of pain can perpetuate a feeling of liminality. Liminality, or the feeling of being neither-here-nor-there, plagues chronic pain sufferers who identify as being neither legitimately ill nor legitimately healthy. Anthropologists have pointed to the concept of liminality as critical in understanding how chronic pain negatively impacts sufferers’ psychological and social well-being (Honkasalo 2001, Jackson 2005, Kuglemaun et al. 2019). Honkasalo states, ‘pain blurs the boundaries between the basic health/illness dichotomy’ (2001: 339). When this line is blurred, individuals with chronic pain can be viewed as subversive because their existence alone questions the linearity and certitude at the crux of biomedical ‘knowing’ (Jackson 2005: 334). YouTuber ‘Annie Elaine’ articulates the concept of liminality and the perception of ‘sick’ stat-

ing, “I am in this weird in-between point of visible and invisible disability... from the outside you might think I look just fine ... I am in pain now and constantly” (2016c, 01:07-01:41). Ambiguity, as Annie Elaine articulates, causes dissidence within the individual with chronic pain. Sufferers grapple with physical symptoms as well as psychosocial effects of not being deemed legitimately ill; the rest of the world is unable to fully perceive what they unwaveringly know to be true (Hay 2010).

Other YouTubers similarly commented on the distress of feeling unwell while looking healthy. ‘aGirlWithLyme’ explained, ‘we may look fine, and not sick at all. It’s our curse to be so sick and still look healthy’ (2016b: 03:14). In YouTube narratives and traditional anthropological studies alike, individuals reflect on being accused of ‘faking’ their

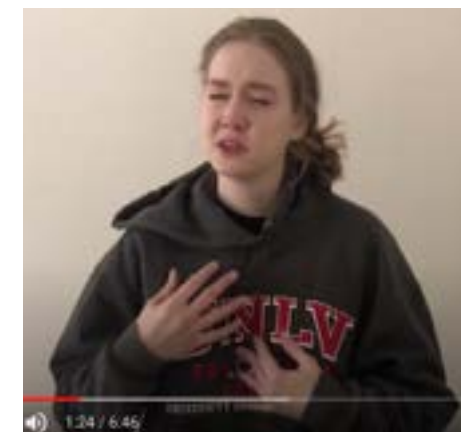


illness and struggling to be seen as ‘authentic’. This is especially pertinent in the context of interactions with doctors who maintain that chronic pain is ‘unreal’ because tests and scans cannot directly point to the origin of the persistent pain (Bass & Halligan 2007: 83). The invisibility of pain, and underrepresentation of pain research in biomedicine, can have deleterious effects on the well-being of a patient with chronic pain (Kuglemaun et al. 2019: 288). Newton et al. writes, ‘the lack of evidence to demonstrate the reality of the individual’s experience may lead others to question the credibility of the patient. Such questioning can affect the sense of integrity that individuals wish to maintain’ (2013: 10). Through individuals’ videos on chronic pain, it becomes strikingly apparent that they are turning to YouTube to tell their stories as a means of putting into action the desire to be seen as credible (Page 2013: 16).

5.3 Capturing Flare-Ups: ‘This is NOT Normal’

One of the most common genres amongst the sampled chronic pain vlogs was the capturing of ‘flare-ups.’ For many with chronic pain, the majority of their day-to-day pain occurrences are invisible yet, occasionally, their pain increases and can manifest visibly. Because sufferers may be confined to their homes, or even bedridden, on days when they experience flare-ups, these scenes of intense pain and illness expression remain unseen to outsiders. One vlogger captured a short video of her hand during a fibromyalgia flare-up explaining, ‘people think that either fibromyalgia is not real, or that we don’t

have pain, or we exaggerate our pain, or that you can’t see pain. But right now this is my body’s response to neuropathy pains, so I thought I’d share’ (The Fibromyalgia Pain Chronicles™ 2019a: 00:33-00:42). Videos like this serve as visual evidence – a means for the YouTuber to prove that their pain is ‘real’ because it can be seen and captured on film. Other YouTube videos capturing flare-ups focus instead on what the emotional experience of being in pain looks like. ‘Live Hope Lupus’ posted a clip from a flare-up prefacing it with the statement, ‘I wanted to show what it’s like– what it can be like– living with lupus. I don’t want people to think I’m being dramatic or trying to get attention. This was honestly how I was feeling at the time’ (2018: 00:47-01:07). Other vloggers echo a similar sentiment that even when they can show themselves during a



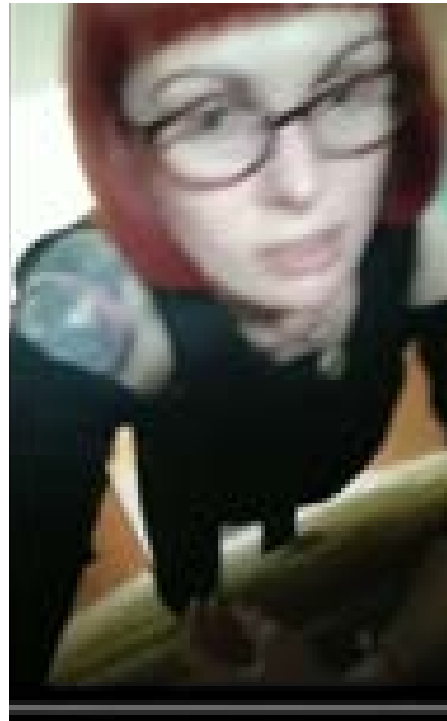
Above: ‘Live Hope Lupus’ captures the emotional and physical experience of a pain flare-up (2018: 01:24)

Left: ‘The Fibromyalgia Pain Chronicles™’ shares a video of her hand during a flare-up (2019a: 00:21).

time when pain can be visualized they still risk accusations of ‘faking it’ or being ‘too dramatic’ (Craig 2015: 29).

Across social spheres, hegemonic expectations lead chronic pain sufferers to mask or hide their pain (Fox 2020: 249). Even discussing pain and illness publicly in Western society can be considered taboo. Vlogger ‘Fibro Warrior’ explained, ‘I felt like I had- I had- to hide it when I was around, so I wasn’t judged, so I didn’t feel like a burden. I wasn’t gonna be looked at like I was being, you know, over-exaggerating’ (2018c, 17:49-18:10). In Naslund et al.’s research on videos created by individuals with serious mental illness (SMI), the authors observed that ‘YouTube served as an environment where individuals with SMI could normalize one’s illness and assert their voice and identity by validating shared experiences with peers’ (2014: 5). Whereas others with stigmatized diseases use YouTube to normalize their illnesses, YouTubers in this study more frequently did the opposite; individuals with chronic pain recurrently drew attention to the fact that their experiences were not normal. In a short clip showing herself attempting to climb up the stairs in the midst of a flare-up, ‘Emma Sharrocks’ contends, (*italics used denote sarcastic tone*) ‘This is not how a f***ing human should live. Obviously, I don’t have a condition. I don’t have a disability. You know this is- this is- f***ing normal. Yeah, this is normal, this is normal’ (2019b, 00:25-00:32). Emma Sharrocks holds the camera, likely a smartphone considering the orientation and dimensions, close to her face. The camera placement as well as the shakiness of the footage give the clip an

‘in-the-moment’ feel, as if the viewer is right there trying to climb the stairs with the vlogger. The vlogger’s employment of a sarcastic tone in conjunction with the intimate, raw footage captures her frustration regarding the disruption her pain causes to ‘normal’ day-to-day tasks like climbing the stairs. The multimodal narrative comes closer to capturing the ‘true’ experience of a chronic pain flare-up in a visceral, emotional manner that would be challenging to capture through traditional written or spoken text alone (Doloughan 2011, Kress 2000, Page 2013, Sunderland et al. 2015).



5.4 Trying to Get Better: Exhibiting Effort

Chronic pain vloggers employ the multimodal capabilities of YouTube to also make visible their efforts to get better. Individuals with chronic pain often express feeling delegitimized by doctors who claim their pain is chronic because the patient has not made an attempt to improve (Good 1992, Hay 2010, Honkasalo 2001, Jackson 2005). Many chronic pain vloggers reflected on how upsetting it is to be accused of laziness and responded by showing their determined efforts to ameliorate their pain (Helman 1984: 76). In one video, ‘Annie Elaine’ attests, ‘I push

myself to do what I can every day. I don’t WANT to be isolated and in pain all day, I often have things I need to get done, but my illness gets in the way’ (2016c, 02:12-02:19). This sentiment reads as a direct response to accusations that sufferers are to blame for the chronicity of their pain.

Pain vloggers use the multimodal format of YouTube to illustrate that their pain persists despite their tireless efforts to improve. In one video, vlogger ‘Greer’s Life’ lists the many strategies she tried to ameliorate her pain, ‘I was doing pelvic floor therapy once or twice a week. I was doing chiropractic. I was going to



Left: ‘Emma Sharrocks’ captures herself trying to climb the stairs during a flare-up (2019b: 00:25)

Above: ‘Greer’s Life’ shows a spreadsheet on her computer that she uses to track her symptoms (2018b: 01:58)

Right: ‘Rebecca Meyer Too’ films herself doing physical therapy exercises (2018c: 01:47)



acupuncture and doing traditional Chinese medicine. I was eating a special diet. I was doing yoga every morning' (2020, 10:52-11:10). In another video, 'Greer's Life' filmed the screen of her computer displaying a spreadsheet she uses to track her symptoms, what she is eating, when she urinates (2018b). Similarly, 'Rebecca Meyer Too' films the physical therapy exercises she does to improve her chronic back pain. The vlogger concurrently narrates, '[I am] trying to do my physical therapy activities, trying to eat right, trying to do anything that I can do in my power, but it just doesn't seem like it's working' (2018c, 01:38-01:55). The use of the visuality of YouTube in this context reiterates the desire of YouTubers to visually prove that they are not 'faking' their pain by temporally illustrating the process of actively trying to heal.

5.5 Visualizing Chronicity

The multimodal nature of YouTube incorporates time-based elements, allowing for the visualization of chronicity. In this study, chronic pain vloggers posted 'Day-in-the-Life' vlogs, a common genre of videos across YouTube. In such vlogs, YouTubers bring the camera with them to show viewers what a 'normal' day looks like. 'Greer's Life,' noted early in one such vlog, 'I feel like everyone does "Day-in-the-Life" or "Get-Ready-with-Me" on days where they look and feel great, and I wanted to kind of show my experience of going through a day in which I wake up from the first breath I take, I feel like I'm in pain' (2018a, 00:04-00:27). 'Olga Chronicles' articulated a similar message in the introduction to her 'Day-in-the-Life'

vlog stating, 'I thought I would do something realistic, and show you what it's like on the days where I don't feel good' (Olga Chronicles 2018d: 00:09-00:25). In these videos the YouTubers are emphasizing that their 'reality' of life with chronic pain is 'abnormal'. By acknowledging their own deviation from the typical 'Day-in-the-Life' videos, these vloggers suggest that their representations are more truthful and 'realistic'; they are not trying to 'look good' or present their lives as flawless. Through this act of 'self-othering' they emphasize that even when pain is invisible, the implications it has on day-to-day life, are undeniable and that pain sufferers' daily lives are anomalous. Thus, videos serve as a window into a world that YouTubers presume outsiders can otherwise not understand.

YouTubers also employ creative multimodal techniques to express the chronicity of their conditions. Through visual cues, and editing functions, chronic pain sufferers venture to address the way that pain is not only physically debilitating for a moment, but also inescapable. In Good's research, interviewees report feeling as though time, a concept usually considered a universal, indisputable aspect of life, is distorted when their lives are overtaken by pain. During times of immense pain, time slows down whereas time outside the body, in a world that the individual cannot access, speeds up (1992: 41). YouTubers may similarly use the diary-like functionality of vlogging to maintain a routine to feel grounded to time markers of the 'real world' (Gonzalez-Polledo & Tarr 2016: 12; Melander 2019: 68).

'aGirlWithLyme' posted a video filmed over six weeks tracking effects of

CBD oil on hechronic pain (2017). In short clips edited together to project a verisimilitude of chronology, she speaks about her fluctuating pain levels and how the oil has been affecting her. Time progression is marked by cuts in footage and changes to the lighting, background, or her clothing. By illustrating the passage of time, the vlog shows the chronicity of living in pain and also highlights the enduring process of trying to treat chronic pain. At the end, she summarizes the overall effectiveness of the product. The incorporation of 'time' corroborates her review, because the viewer has witnessed her navigate the process of testing the product. Through sharing their illness narratives and transitioning from 'not-knowing' to 'knowing' over the course of the stories, vloggers can present themselves as having learned from their experiences in a way that prepares them to share their knowledge with others (Melander 2019: 83).

BEING SEEN AND BEING SEEN AS 'EXPERT'

As opposed to other social media platforms that focus on social engagement with others and the sharing of resources, YouTube offers pain sufferers a distinct opportunity to 'be seen'. Individuals grappling with rare diagnoses frequently turn to social media platforms like Facebook groups and online forums to connect with others across the globe with parallel symptoms. Many of these groups are private with entry is permitted exclusively to those with a specific diagnosis. The em-

phasis of such groups is to share wisdom, advice, and social support. Users with diseases like cancer, HIV, and diabetes can find a 'safe-space' away from outsiders who may not understand their experiences (Huh et al. 2014, Liu et al. 2013). Even vloggers in this sample comment on how they frequent other platforms for seeking support; 'Rebecca Meyer Too' explains, 'I have an amazing support group that I found on Facebook from people with herniated discs, and honestly, like they're just like my go-to people for like every question, and they have every answer' (2018b, 02:05-02:20). It seems unlikely that individuals would turn to posting on YouTube solely for its social capacity when there are other platforms that support biosocial communities without the heightened risk of exposure to criticism (Fox 2020: 254).

Berryman and Kavka emphasize the way visibility is valued differently on YouTube noting that the platform places 'a premium both on showcasing one's physical appearance and disclosing intimate information about the self' (2018: 95). While many YouTube users never post content and remain relatively anonymous, vloggers make themselves and their pain distinctly visible (Page 2013).

6.1 Exposing the "Ugly" Truth

Across many cultures, individuals are expected to refrain from expressing the pain they feel in the public domain. Acknowledging that one is in pain is considered to be an admission of weakness and the recognition of a body's failures and imperfections. In line with these tendencies, social media is dominated by health discourses centered on topics like healthy eating,

exercise and anti-aging posted by ‘influencers’ who are physically fit, and exude youthfulness (Berryman & Kavka 2018: 90). Thus, it is even more intriguing that individuals with chronic pain decide to post publicly, in spite of their pain (Fox 2020: 251). YouTube creators are highly visible, self-disclosing their struggles to viewers who are protected by anonymity. In many regards, YouTubers with chronic pain could be seen as placing themselves in an even more vulnerable position, and yet, in many instances it seems as though the opposite is true (Huh et al. 2014, Liu et al. 2013). YouTubers who post about their chronic pain do so boldly and intentionally; they share videos of their faces and bodies to make their pain irrefutable and in doing so, work to reclaim authorship of the narrative of their invisible illnesses. Rather than being silenced by the discourse that expressing pain discloses weakness (Fox 2020), chronic pain vloggers capitalize on negative affect to evoke empathy and assert authenticity to their viewers.

Social media is castigated for propagating an artificial feed of ‘endlessly positive self-documentation’ wherein ‘influencers’ promote unrealistic standards of beauty and success (Berryman & Kavka 2018: 85). Negative self-representations resist the canonical positivity that is ubiquitous on social media. As Berryman & Kavka reflect, ‘if forced positivity is fake, then unforced negativity must be ‘real’ (2018: 90). Through showing themselves as imperfect, chronic pain vloggers can present their narratives as ‘raw’ and unaffected (Huh et al. 2014: 11).

The face-to-face vlog format allows for intimacy, reminiscent of ‘real life’ communication, except of course, that it is predominantly unrequited. When vloggers address the camera they utilize facets of in-person conversation (Tolson 2010: 279). Vloggers retain extended pauses, stammers, and tearful moments even though they could edit them out (Huh et al. 2014). The glimmers of ‘real life’ are maintained to reiterate the idea that the vlogger is presenting a window into her world. Chronic pain vloggers express their emotions, especially the negative ones, in order to portray their online-selves and in-person selves as synonymous. Vloggers address their feelings of guilt: ‘there’s like a lot of guilt in chronic pain and there’s

a lot of guilt in mothering, so combining the two, it’s like guilt central for me’ (Penney Brand 2016b: 07:24-07:32), their fears: ‘I hope you guys understand more of what it’s like to have lupus. It’s scary– it’s– it’s– not an easy thing to think about’ (Live Hope Lupus 2013b: 02:38-02:50), and the fact that they are struggling, ‘everything’s really hard for me right now’ (Rebecca Meyer Too 2018e: 05:36-05:41). Through exposure and emotional vulnerability, vloggers can foster a presumed emotional connection with viewers, making them feel drawn into the chronic pain sufferer’s world (Berryman & Kavka 2018: 90).

6.2 Acknowledging the Audience

For chronic pain vloggers there is a range in their audience engagement. Some vloggers receive no comments on their videos, while others frequently field questions from viewers and participate in exchanging advice in the comments section. Some vloggers, like ‘aGirlWithLyme’, instigated engagement: ‘I have a question for you, what does ‘sick’ look like?’ (2016b: 06:26). While questions like this do not specifically presuppose who the audience is, other vloggers directly indicate their intended audience: ‘this channel is all about raising awareness and educating able-bodied people about invisible conditions’ (Emma Sharrocks 2019a: 01:50-54). Many vloggers shared this goal and would direct their messages towards individuals who may not understand or believe chronic pain. ‘Annie Elaine’ implores, ‘please re-evaluate what you think about disabilities and what you think disabled people look like because we all look different’ (2015: 04:02-04:10). Statements by vloggers who actively engage with their mostly anonymous audience reflect the motivations underpinning

the desire to make one’s pain experiences visible. There is a clear need presented by vloggers to not just connect with people experiencing similar struggles, but to appeal to those on the ‘outside’ who cannot see chronic pain and thus do not believe it is real (Bicquelet 2017: 332; Page 2013: 30).

6.3 Authoring the Story: Reclaiming Chronic Pain Narratives

Beyond attempts to enlighten and influence ‘outsiders,’ chronic pain sufferers also reflect on being able to educate others who may be seeking chronic pain advice. Utilizing story-telling tactics to distinguish between the past and the present, as well as emphasizing the positionality of the visible creator and invisible, anonymous audience, chronic pain vloggers are able to present themselves as experts. They not only are able to make their pain seen, they also have agency over how they are seen and how their pain is seen. Fox argues, ‘patients may not be able to stop their pain, but through video, they can become its director. Patients can choose what forms of performing pain are meaningful and valid for them, rather than following a prescribed template (2020: 255). Indeed, chronic pain vloggers apply aspects of ‘typical’ YouTube engagement, for example the ‘Day-in-the-Life’ vlog format, while disrupting the hegemony of only showing positive aspects of one’s life on social media (Berryman & Kavka 2018). They are also able to tell what they believe is the entirety of their story, without risk of interruption. The human desire to share stories is considered universal (Doloughan 2011: 15). Thus, the inability to share stories about pain, whether due to societal expectations regarding the disclosure of pain or the minimizing by one

YouTubers
who post
about their
chronic
pain do so
boldly and
intentionally

who deems pain ‘unreal,’ keeps individuals from experiencing a fundamental aspect of human life (Bicquelet 2017: 332). Through self-published illness narratives, vloggers are reclaiming their voice and the authority to share stories about what they are experiencing in a way that seems ‘valid’ or ‘real.’

The internet has become a primary source of reference materials for individuals seeking advice regarding nearly any issue. The combined universality and accessibility of the internet can make it virtually impossible to discern between ‘expert opinions’ and ‘consumer experiences’. On YouTube, where ‘do-it-yourself’ videos are ubiquitous and blur the line between expert and amateur, the phenomenon is intensified (Bicquelet 2017: 333; Tolson 2010: 287). Vloggers can employ editing techniques and visual effects to make their videos appear more

professional, substantiating their authority when making claims and providing advice. Kugle et al. write, ‘via social representations, patients assert the authority of their experience and take up the ‘subject position’ and assert truth about chronic pain, despite the fact that they are not the experts” (2019: 291). Vloggers are using a platform upon which they have likely witnessed other ‘ordinary people’ sharing experience-based expertise and being received as figures of authority. While there is undoubtedly a risk of sharing misinformation there too is value in bridging the gap between the ‘lay knowledge’ of individual experience, and the biomedical, ‘expert,’ discourse (Gibbon & Novas 2007: 8; Padfield 2011: 249). This is especially salient regarding illnesses for which the common narrative lacks sufficient answers for so many sufferers.

6.4 Making and Unmaking the ‘Doctor’ Role

YouTube users with chronic pain reflect upon negative encounters in medical settings, and the challenge of getting a diagnosis. They share ‘incompetent doctor stories’ to position themselves as ‘experts’ of their pain narratives. Chronic pain YouTube users actively engage with the biomedical discourse of chronic pain as a way to highlight the faults and ineptitudes of medical professionals’ understanding of pain. Ida Melander observed a similar practice in Instagram-based illness narratives claiming, ‘by voicing “unreasonable” advice, the tellers position themselves as knowledgeable’ (2019, 86). Many vloggers recounted doctors who dismissed their pain because they could not see or could not measure pain and thus it could not be diagnosed as a ‘real’ condition according to their biomedical understanding.

Chronic pain sufferers’ endure many years of doctor’s visits, tentative diagnoses, medical interventions, hope, and disappointment. Through outlining recurrent instances when doctors failed to reach a diagnosis due to the invisibility of chronic pain, they posit that the inability to see and understand pain is an indication of an incompetent doctor. They are able to argue that the impetus is not that the pain is invisible, but that the doctor is ill-equipped to understand a symptom despite its invisibility. ‘Annie Elaine’ shares a story of feeling spurned by a doctor stating, ‘I told the doctor my story, how much pain

I was in, how it was limiting my ability to walk, his response was “Well, what you want ME to do about it?” That line felt like such a betrayal. I had waited for so long, I was so scared and in so much pain and I just got treated like a joke’ (2017a, 6:16-24). ‘Annie Elaine’ emphasizes her doctor’s inability to hear her story and provide adequate treatment. She illustrates the idea that the doctor could have helped her had he comprehended and believed her story. ‘Fibro Mom’ highlights the frustration of a doctor not grasping her attempts to share her illness narrative stating, ‘I had a doctor who didn’t understand what I meant that every morning, when I wake up, and I go to take a step out of bed, it feels like I’m stepping on broken glass’ (2012: 02:27). While the vlogger feels that her articulation of pain is clear and comprehensive, she is able to shift blame from herself (the ‘irrational pain patient’) to the doctor who does not understand her illness.

While pain vloggers frequently critique the doctors who were unable to treat them, they often ascribe biomedicine as containing the answers to their pain, the assumption being if doctors understood, then they could provide treatment to fix chronic pain (Newton et al. 2013). Pain vloggers fluctuate between using stories of negative interactions with doctors to show the ineptitude of doctors in acknowledging the reality of chronic pain to using positive doctor-patient stories to validate the reality of their pain. ‘Penny Brand’ references her doctor in order to emphasize her own authority claiming, ‘straight

I was so
scared and in
so much pain
and I just got
treated like
a joke

from the mouth of my surgeon and my pain specialist, pain is real. They’ve both said that, you know, it’s not just something that you’ve made up’ (2016e, 02:18-02:26). Other YouTube users posted videos of advice on ‘how to make doctors believe you’ and emphasize the need to be persistent and confident in medical settings (Izzy Kornblau 2018c, Live Hope Lupus 2017a). Some vloggers posted videos outlining the diagnostic criteria for their specific conditions. In the comments sections of these types of vlogs, viewers’ questions validate the image of authority that vloggers convey. In a comment on ‘Live Hope Lupus’s’ video (2017a) a viewer asks, ‘My ANA was 1.62 or something like that with a homogeneous pattern. Is that high?’ Comments along this vein contribute cyclically to a vlogger’s ability to be seen as an expert. Vloggers respond to viewers, either in the comments section or within the content of their vlogs, using biomedical information to affirm the knowledge they have attained through their own experiences and/or research (Gonzalez-Polledo & Tarr 2016, Ressler et al. 2012).

MAKING MEANING AND FINDING PURPOSE

Chronic pain sufferers turn to YouTube in order to share multimodal illness narratives substantiating their claim that invisible pain is real. In doing so, they work to resist hegemonic views of disability and chronicity and assert control over how they are seen. Consequently, YouTube has become a significant domain for meaning-making surrounding invisible chronic pain experiences.

Anthropologists' cross-cultural work on chronic pain has recurrently addressed the desire of sufferers to find 'purpose' in illness and pain (Good et al. 1994, Honkasalo 2001, Kleinman 1988, Throop 2018). Reframing one's disability or suffering into something productive or meaningful can have profound effects on the embodiment of pain (Lynch et al. 2013) as well as the social and emotional implications on a pain sufferer's wellbeing (Brokerhof et al. 2020, Campbell et al. 2003, Good et al. 1994). Jason Throop's work with Yapese people echoes the socio-cultural context that sets exceptions for how the way that pain is spoken of can significantly alter the perception of pain and the pain sufferer's wellbeing. In Yap, *maath'keenil*, back pain translated literally to 'severed spine', is recognized as the result of hard work and is considered to represent 'suffering-for' the individual's family and greater community (2008: 268). Throop observed that amongst the Yap, framing pain as *maath'keenil* rather than

'mere suffering' allowed sufferers to 'gain moral worth' (2008: 270). Throop's study illustrates how the language and cultural attitude surrounding pain can shift the burden pain poses to sufferers. The concept of giving purpose to one's pain manifested in many YouTubers' narratives. Several vloggers shared statements resembling, 'hopefully this video will help someone' articulates the idea that an individual's pain can be made more meaningful, and is less stigmatized, if it serves a function beyond the individual (Huh et al. 2014, Liu et al. 2013). The extent to which an individual's social world is affected by their chronic pain depends on an individual's ability to label and grapple with the ambiguity of chronic pain, and the way pain is given meaning through culture (Honkasalo 2001). As Good states, 'when pain is chronic, it extends into the world, shaping the world to itself. The world of pain becomes a special world, a world largely unshared and un-sharable' (1992: 47). In a way, pain sufferers are able to bridge the world within their body and that outside (Jette 2017: 1).

the language surrounding pain can shift the burden of pain

Anthropologists and psychologists have further contended that writing and speaking about one's illness can be therapeutic (Charon 2008, Fox 2020, Kleinman 1988, McGrath et al. 2011, Page 2013). The vloggers in this study often mentioned their motivations behind sharing videos; 'aGirlWithLyme' reflects on the process of vlogging stating, "it has kept my mind off the physical pain for quite a while... it's also been a great outlet for me to talk about my journey and my struggles and to share my story' (2016a, 03:09). Similarly, 'Rebecca Meyer Too' explained, 'for those few minutes for those few hours that I'm playing around with video, I can take myself out of the actual pain' (2018d, 00:57-01:02). The process of creating a work of art or completing a physical product can help chronic pain sufferers renegotiate their identity in order to regain their sense of control (Lynch et al. 2013: 67). Likewise, through social media, pain sufferers have the opportunity to, literally, be the directors of their narratives; this sense of agency can allow individuals to feel more confident and empower them to share necessary perspectives recurrently excluded from medical research and practice (Padfield 2011: 254).

CONCLUSIONS

Vloggers are not only using YouTube as a way to be seen, but as a way to gain control over how they are seen. Brita Ytre-Arne describes traditional health blogging as 'a pressure-relieving outlet, made necessary by an illness that confines patients to their homes and to their own minds' (2016: 61). Through YouTube, vloggers who are

physically unable to engage with the 'outside' world in the way others without pain do, can be 'publicly' visible while being confined to their homes. Creating a YouTube video also culminates in a visible end product. Regardless of who sees the video or who digests the message, it is a tangible product being put out in the world. They are able to present themselves as productive, efficacious individuals despite physical barriers cause by chronic pain. (Ressler et al. 2012: 2; Ytre-Arne 2016: 57).

While chronic pain sufferers often feel silenced or ignored in biomedical spheres, patient-led online communities have the potential to help individuals develop a new multimodal vocabulary to express pain and can empower them to feel confidence voicing their experiences of pain. Other anthropologists and social scientists have argued for the potential social media serves as a tool to bridge communication gaps between patients and physicians (Gonzalez-Polledo & Tarr 2016, Jette 2017, Luzzato et al. 2003) as well as the value of multimodal illness narratives in allowing for more dynamic, holistic, and authentic pain communication (Kleinman 1988, Mattingly 1998, Ressler et al. 2012). Individuals are drawn to YouTube because video is a distinctly multimodal medium. Creators of videos are engaging with the platform in order to make their pain seen, heard, and above all, believed. This contrasts to other scholars' research on social media and illness narratives that employ a lens of biosociality and focus predominantly on social media's benefit to those seeking advice and a supportive community (Kugleemann et al. 2019, Melander 2019, Ressler et al. 2012, Tolson 2010). While YouTube has undoubtedly also become a

biosocial community for individuals with similar conditions to communicate, empathize, and share advice, it is evident that vloggers are also using YouTube as a platform to appeal to, and educate, others who do not have, or do not understand, chronic pain.

Whereas this paper focuses on the motivations and intentions of vloggers who chose to post chronic illness narratives on YouTube, the findings of this study point towards many other potential avenues for future research. Multimodal illness narratives, especially those found on social media are a largely untapped resource for medical anthropologists. Social media provides a wealth of data that has the potential to transform biomedical understanding especially in regards to doctor-patient engagement (Heathcote et al. 2018: 19). Especially for topics like chronic pain that can be difficult to articulate, or that are received with distrust or disbelief, traditional data collection strategies often fail to capture the patients' distinct experiences. The way pain is understood, endured, and addressed varies significantly across populations (Throop 2018, Honkasalo 2001).

Ethnographic research and digital forms of ethnography can facilitate the formation and dissemination of illness narratives and can serve as a catalyst, shifting the dialogue of chronic pain from exclusively biomedical definitions to one that accounts for patient experiences. It is only through listening to patients and individuals experiencing chronic pain that the reality of pain becomes evident (Charon 2008, Good, 1992, Kleinman 1988). While this paper posits that YouTube, through its multimodal nature, allows for the inclusion of a wider range of voices in the medical discourse of chronic pain, there

are still many perspectives missing from the cannon (Ravelli & Van Leeuwen 2018: 289). Integrating patient-led narratives into the biomedical discourse of chronic pain is just one step towards the greater goal of more inclusive, diverse medical understanding.

it is only through listening to patients and individuals experiencing chronic pain that the reality of pain becomes evident

Appendix 1: Demographic data of the first selection round, n=58 YouTube channels.

Gender:		Chronic Pain Condition/Pain Type:	
Male	7%	Ehlers-Danlos Syndrome	10%
Female	93%	Fibromyalgia	33%
Age:		Auto-Immune or Genetic Disease	7%
Under 25	16%	Endometriosis or Unspecified Pelvic	10%
25-40	66%	Other: Back Pain	7%
40-55	14%	Other: Head and Neck	22%
55+	5%	Unspecified or Undiagnosed	10%

YouTuber's Total Channel Views*:

Average	2,589,929
Min	67
Max	64,455,928

* Channel views as of July 26, 2020.

Appendix 2: Demographic distribution of final sample (n=12 YouTube Channels; 72 Videos)

	Video Duration (minutes)	Video Views *	Channel Views *	Subscribers *
Average	8:43	19,753	522,307	5,665
Min	1:12	76	1,685	50
Max	23:36	321,921	2,230,666	21,600

Gender:		Age	
Male	0%	Under 25	17%
Female	100%	25-40	58%
		40-55	17%
		55+	8%
Chronic Pain Condition/Diagnosis:		Nationality	
Ehlers-Danlos Syndrome	17%	American	58%
Fibromyalgia	42%	Australian	8%
Lupus	8%	British	17%
Endometriosis	8%	Canadian	8%
Other: Back Pain	17%	Portuguese	8%
Chronic Lyme Disease	8%		

* All YouTube popularity data retrieved on August 4, 2020.

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