

## **Chronic media worlds: social media and the problem of pain communication on Tumblr.**

This paper explores dynamics of pain communication in the social media platform Tumblr. As a device of health communication, the Tumblr platform brings together a network of behaviors, technologies and media forms through which pain experience is reimaged through and against mainstream biomedical frameworks. The article develops an interpretative approach to analyze how, as social media platforms reorganize affective, emotional, physical and temporal frames of experience, communication about chronic pain and illness is reimagined in its capacity to create, and subvert, pain worlds. Drawing on ethnographic theory to reimagine the relation between politics and poetics in pain communication, the article explores the issue- and world-making capacities of social media.

Keywords: Tumblr, social media, chronic pain, chronic illness, pain worlds

### **Acknowledgements:**

This research was funded by the ESRC National Centre for Research Methods under the Methodological Innovations Projects scheme (Grant number DU/512589108).

I extend thanks to my co-investigators in this project: Jen Tarr, Flora Cornish and Aude Bicquelet, for their support and insight. Thanks very specially go to Ricardo Carvalho and Lutz Issler for their work on the Tumblr visualization proof of concept, and to Tumblr for allowing our project to host the application on our website for research purposes.

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## Introduction

Chronic pain is arguably becoming a ubiquitous condition of our time. Foreman (2013), following a 2011 report signed by the Institute of Medicine, estimates that one hundred million Americans live with chronic pain, while in Europe, Breivik *et al* (2006) conducted a survey across 16 countries and report that 19 % of adult Europeans admit to suffering a form chronic pain, and having their quality of life and work seriously affected by living with non life threatening chronic illnesses. Although there is agreement among experts defining ‘chronic’ pain as encroaching a 3-month time threshold of initial pain onset, chronic pain is notoriously difficult to standardize, since it may be caused by a wide array of processes, both nociceptive and neuropathic, and its intensity and quality depends on subjectively constructed modular responses (Melzack and Wall 1965; Moayedi and Davis 2013). Although the experience of pain has common features, and standards have been usefully deployed in diagnostic practices<sup>i</sup> to improve clinical pain reporting, individuals can perceive pain differently according to emotional and cultural factors, their particular biopsychosocial makeup and the incidence of co-occurring conditions.

While working medical definitions have evolved to include linguistic nuances that establish differences in the intensity and quality of pain experience, there are still multiple dimensions that elude standardization under current clinical protocols (Melzack 1983; Turk and Melzack 2011; Wall, Melzack and Bonika 1994)<sup>ii</sup>. Indeed, the relation between pain and language has been recurrently problematized. In her enormously influential study of pain, Scarry argued that feeling pain and sensing others’ pain are experiences so far apart that across these experiences the effects of pain become polarized, its ‘accomplishment’ diffused<sup>iii</sup>. From this perspective, pain takes no object, and no referent, since the very process of communication inevitably entails the dissolution of pain experience. However, multiple clinical studies of language based clinical communication (Biro 2010; Sullivan *et al* 2004; Smith *et al* 2006; Main and Linton 2013; Kenny 2004; Eccleston *et al* 1997; de Boer *et al* 2007; Squire 2007, among others) suggest that people in pain often report different capacities to communicate about pain in various material and clinical settings (Rowbotham *et al* 2013; Jackson 2000; Coakley and Shelemay 2007; Kall 2012), suggesting that clinical uses of language and gesture can sometimes positively affect diagnostic and management outcomes. Acknowledging the gap between experience and language, which can make pain communication difficult or impossible in some instances, Grahek (2007) has shown that communicating about pain is often as much about associating a communication frame and a lived experience, as it is about their dissociation, and thus making sense of the difficulty of communicating pain, which ordinarily involves connecting subjective and phenomenal states<sup>iv</sup>, does not always make communication inviable. After all, as Goffman (1978) argued, responses to pain are polyvocal, and while response cries indicate that pain *is* happening, they do not whether pain is

physical or emotional, whether it is happening or about to happen, or if they respond to a memory or to the immediate presence of pain.

And yet, it is clinical language and measurement tools used in clinical contexts that inform both clinical practice and policy, and have an effect on users' capacities to access diagnosis and treatment. As pain is routinely assessed and the outcome of assessment warrants access to services, the meaning, function and effect of pain communication effect the transduction of 'flesh into words' (Gere and Parry 2006, see also Bourke 2014) that responds to the never value neutral processes through which 'a body becomes a 'body of information', a data gathering instrument to gauge the viability and efficacy of care interventions<sup>v</sup>. Carel and Kidd (2014) observe that in clinical contexts pain communication is often framed by structural forms of epistemic injustice built in in healthcare practices and frameworks, which affect one to one clinical encounters. When communicating about their illness in a clinical context, they argue, illness sufferers are often recipients of testimonial injustice, particularly when met by prejudice, or when their frames to communicate about illness are deemed irrelevant, time-consuming, emotional, insufficiently articulate or unhelpful (Carel and Kidd 2014). Carel and Kidd argue that this type of epistemic injustice situates the issue of clinical communication at the top of complaints recorded by patients associations<sup>vi</sup>, and while it cannot be 'blamed' on one to one clinical encounters, its prevalence can be traced to liable policies, practices and cultural norms in healthcare practice.

This article shifts the focus from clinical environments to social media to ask whether, and how, communication about pain is significantly transformed beyond the constraints of clinical relations. Exploring the *difference* that social media makes to living with forms of persistent, non life-threatening pain, I argue that in social media pain is reframed as a political issue as it is transformed from an individual, potentially disabling event that has the capacity to put life on hold to an inherently social, actionable, collective *issue*<sup>vii</sup>. Displacing the need to define pain through biomedical frameworks and demonstrate its 'realness', social media are increasingly becoming health devices where the experience of living with pain is normalized and made newly visible. Social media invite us to think pain not as a one-off, catastrophic life-changing event, but as a way of being in the world *with a difference*, making things and processes which would have been imperceptible to others 'the scandal of the everyday' (Das 2014:281). In their capacity to make pain worlds, this article argues, pain communication opens up the political capacities of social media, as people living in pain actively resist epistemic injustice and create inhabitable pain worlds<sup>viii</sup>. In this sense, social media could become a focus of a new research agenda, as Ginsburg and Rapp suggest, that thinks beyond disability paradigms that locate disability only in relation to the medical gaze, to a recognition of 'disability worlds' that privilege new lenses and recognize 'the difference that disability makes' as an essential form of human diversity (2013:182).

## **Pain worlds in social media**

Social media platforms provide an ideal setting for the becoming of ‘pain worlds’. They are accessible, cater to a worldwide user base, and are often ideal environments for the formation of communities of interest. Indeed, in social media, chronic pain forums, groups, and communities of interest are proliferating at a rapid rate. Moderated Facebook groups dedicated to one or a combination of conditions offer practical and emotional support to those living with symptoms; YouTube offers an abundance of first person narratives, how-to videos, experiential advice and services. Image hosting services have accrued an unprecedented wealth of images relating to living with pain and illness, making visible dimensions of pain that were hitherto seldom made public<sup>ix</sup>. For this reason, new media devices are increasingly becoming an important focus of analysis in health research<sup>x</sup>. As Mazanderani et al (2012) have observed, users increasingly turn to social media to find forms of peer support as a source of experiential knowledge about their illness, finding ways to overcome tensions caused by differences in their experience with a shared sense of being ‘differently the same’. Mazanderani and Papparini (2015) have highlighted the role of digital media as ‘confessional technologies’, at once normalizing illness and creating new forms of selfhood as a response to engaging issues, coping and ‘working on’ the self living with illness. These devices may include forms of peer support, counselling, forms of participatory research and testimonial practices.

Indeed, online devices are also changing what it means to live with a chronic illness. Working with women blogging about Multiple Sclerosis in the US, Sosnowy (2014) notes that while blogging offers opportunities to patients to share information and connect with others, it is often also a disciplinary practice which reproduces a discourse of self-responsibility. Other researchers highlight the community-making capacities of online devices. Ressler et al (2012), in a survey of blogging practices of people with chronic illnesses, found that motivations for blogging, as well as the function of illness blogs change over time around dominant feelings, where blogs could begin as ‘quest narratives’ (Frank 1995) to later become mentoring or support networks for users. Gonzalez-Polledo and Tarr (2014), comparing pain communication on two social media platforms, have argued that illness narratives are not so much characterized by traditional modes of patient-doctor co-construction, but challenge narrative convention and form by using multiple representational frames, creating real and imagined ‘networked publics’ (boyd 2010) around chronic pain.

This study focuses on the participatory, stream based, microblogging social media platform Tumblr. Founded by David Karp in 2007, Tumblr distills the functionality of tumble logs – favoring short, mixed media messages over longer text based commentary- with a strong emphasis on design and customisation options for users<sup>xi</sup>.

These features have made it attractive to a rapidly growing user base<sup>xii</sup>. Users create their blogs not by posting new content, but by appropriating circulating images, videos, gifs, audio, and text images, sometimes altering and annotating these pre-existing media forms. Despite sharing into one or several communities of interest formed online, Tumblr users do not have to be known each other offline in order to ‘follow’ them and access their content. Individual blogs display eclectic mixes of memes, photographs, audio clips and quotations. Unlike traditional blogging platforms, users do not usually talk at length about their experience of illness, but rather construct their experience by relating to content posted by others that often relies highly on shared visual cultural codes. Through the user interface, each user accesses a stream circulating ‘images’, and I use this term, following Wagner (2012) to include also language figurations, which partially link multiple themes, referents, issues and users.

In part, the development this online community has been made possible by the particular qualities and affordances of Tumblr’s development as a social media platform. It has been argued that software development determines the scope and shape of interactions by adding functionality, particular aesthetics and politics that both enable and limit online sociality (Bucher 2013; Fuchs 2014; Gillespie 2013, Munster 2013). On Tumblr, a strong emphasis on visual aesthetics coupled with an unmoderated environment where it is possible to post and collect all types of adult and ‘not safe for work’ content has privileged the circulation of memes, has promoted a culture of participation where humour and sarcasm can challenge limits of mainstream cultural narratives about illness<sup>xiii</sup>. Van Dijk (2013) has noted that while the creativity that goes on in these platforms is nothing new, what were once fleeting or casual remarks have now become formalised inscriptions, taking on different values as they become newly accessible, regulated, or reclaimed over time (Kaun and Stiernsted 2014), sometimes by prying service agendas removed from the initial communication intent (Lupton 2014).

Following Rabinow and Marcus, I propose to focus on how these networks create a ‘space of the contemporary’ (Rabinow and Marcus 2009; cf Bachelard 2002), a real time co-existence between users, technologies and media punctuated by communication rhythms and ruptures. The social network provides both a shared sense of time and at the same time form a kind of anti-temporality (Turner 1985), a place where the world as it is known is effectively reversed, and where new worlds are made in collectively sharing and acting differently upon the experience of illness. As the collective temporalities of the network displace the centrality of coherent first person narratives, networked content becomes a key unit of analysis that challenges assumptions, values as well as notions of the self in pain (Morley 2010). Indeed, ‘media ecologies’ (Fuller 2005), shift the focus from ‘new media’ objects as discrete and independent to processes of mediation that link multiple dynamic and interlocked processes, both biological and socio-cultural. Kember and Zylinska think through the relationality of media ecologies in terms of the mutual co-constitution of the human and the

technological (2012:12). In this context, the self is made in the opening possibilities of mediation as a performative becoming: a distributed embodiment across agents, media and technologies, where creativity derives from the ‘true’ becoming together of these ecologies. For Kember and Zylinska, this emphasis on relations is radically constitutive, and it has consequences to rethink the moralities and ethics of new media.

Indeed, focusing on media dynamics, this article explores how communication on Tumblr could be understood to operate a figure-ground reversal, a play between background and foreground that alters assumed relationships between narrative and self, and between images and meaning. While it could be applicable to social media communication more generally (Galloway, Thacker and Wark 2013), figure-ground reversal is particularly relevant to chronic pain communication, because, as Jackson has argued, chronic pain evinces ‘the incommensurability between embodiment as lived and embodiment as represented’ (Jackson 200:168). The anthropologist Roy Wagner (2012b) described figure-ground reversals in the intensely visual culture of Barok as situations where an image’s interpretation becomes secondary to the image itself. Instead of focusing on interpretation in the first instance, for Barok the image ‘has the power of eliciting (causing to perceive) all sorts of meanings in those who use and hear it, as well as the power of containing all possible meanings that may be so elicited; for the image itself, and only the image itself is equal to all of them’ (2012b:536). For Barok images themselves take the central place of meaning interpretation, and thus it is images Barok transform, further synthesizing their significance<sup>xiv</sup>.

Chronic pain microblogs are made up by sets of circulating content that is framed as made relevant to *ways* of living with pain, highlighting not only aspects of what a preexisting experience of pain feels like, but ‘making’ chronic pain as a distributed experience in the coming together of actors, issues and publics. Shifman (2013) associates memetic communication in the Web 2.0 with increased public participation in mainstream culture, based on repackaging, remixing and imitating. For Shifman, this process happens as people process information through the senses, and then pass that information on to others, who advance new versions of memes that reproduce both content and a set of behaviors. Memes, as vehicles of communication, are both artifacts and messages (Shifman 2013; Blackmore 1999). For Shifman, ‘the ways in which [meme] addressers position themselves in relation to the text, its linguistic codes, the addressees and other potential speakers’ (2013:40) represents a meme’s stance, a capacity that can set in motion imitative practices that reproduce its content and communicative mode. Through stance, chronic pain memes not only *relate* to the context in which they are produced, but contribute to creating it by conjuring up around themselves a material context that can draw public responses. I argue that, in this sense, chronic pain communication on Tumblr becomes a form of political action: a performative capacity of collective framing that results in making issues public. Marres (2006) identified issue formation as central feature in ICT mediated relations, since it is

through ICTs that political communities of people that don't socialize together are formed. She suggests that to understand how issues are articulated in a network demands a consideration of the processes whereby 'issues take on special importance as providing, enabling or even necessitating connections among actors' (2006:6), sometimes inciting mobilization, emphasizing technologies of filtering, positioning and serendipity through which issues are framed. Indeed, the capacity of online networks to facilitate the discursive shaping of values around disability has been identified as a core feature of the making and mainstreaming of online disability cultures (Goggin and Newell 2003), since processes of online participation have the potential become affirmative, creative and diverse spaces, through they also have, in some instances, evolved to become segregated specialist spaces.

## **Methods**

This research was developed during a two-year period. I chose Tumblr as a research site after a wide survey of pain communication on social media platforms, for two reasons: because of the prevalence of mixed media content in the network, and because of the high number of chronic pain related and blogs. Unlike other social media environments, Tumblr users' blogs have front pages hosted in publicly accessible URLs, though content in Tumblr can only legitimately be accessed within the network, to comply with Tumblr's terms and conditions. I established an online presence creating a research blog which displayed link to my research profile. I then followed over 1120 blogs that regularly posted content about chronic pain and chronic illness, searching keywords and surveying the content stream of real time posts generated by these users. As my network grew, I found more bloggers through the network, following links on posts to profiles from which a given post had been reblogged.

Many bloggers in this network identified themselves as people living with chronic illnesses, some indicating in their blog descriptions their place of residence, gender identification, and age; others by listing the chronic condition(s) they suffered from, yet others cataloguing their tumblr profiles as 'chronic illness' blogs. Most of these users self-identified as female, although less often men and trans identified bloggers appeared on the stream. While consistent with illness blogs in other platforms (Ressler et al 20120, some bloggers presented their blogs as an illness narrative (Frank 1995), yet, since by definition chronic pain narratives often do not lead to restitution, illness was more commonly described either as a chaotic situation that upset the rhythm of life enjoyed prior to illness onset, undermining agency, or as a spiritual quest journey where there was some meaning to be found in spite of hardship. Other bloggers post material about chronic illness less frequently, interspersing illness related content with cultural and lifestyle interests. I also regularly searched general hashtags around chronic pain and illness, as well as illness-specific hashtags. However, real time surveillance of the

content stream reveals that often chronic pain related content is not hashtagged. Since images and memes can refer to pain ambiguously, this can make it difficult to identify that content relates to chronic pain, which demonstrates that the difficulties of communicating about pain described earlier in the article do not entirely dissolve in digital environments.

I posted content on the stream and interacted with bloggers via ‘notes’ (reblogs and likes) and personal messages. Deciding which materials could be displayed on my research blog involved two kinds of decisions, around the relevance of posts to chronic pain, as discussed above, and how best to protect users’ privacy. Carefully considering the ethical implications of sharing personal images of pain and vulnerability, I reblogged only content that was already anonymous or could be anonymized. There are no formal privacy toggle controls on Tumblr for blog posts that are published (all posts have permalinks), and because it was not possible to establish private correspondence with all the bloggers I interacted with, I only reblogged content that did not expose identifiable information (either descriptive verbal accounts or identifiable images). Even though it is difficult to trace copyright in images shared by thousands of people, here I refer to these images using permalinks that link them to one of the blogs in which they were published. I also refer to bloggers by their chosen usernames.

I posted new several times per week, at different times of the day. After two years, the blog had accrued over 800 followers. During this period, I developed an ethnographic approach to capture naturally occurring conversations and interactions around content (cf Boellstorff 2012), using the means users employ most: note counts and added text notes. The collection of items on this blog later became the main dataset for the visual thematic analysis I describe in next two sections (accessible at <http://www.communicatingchronicpain.tumblr.com/>). As I observed posting dynamics, reblogs emerged as key function; de facto, a *mode* of communication on the platform. Since every post was shared, then reblogged with modifications by multiple users, understanding more the reblog process in context became a key research question. Using Tumblr’s RESTful API as the main data source, our team developed an application to visualize content reblogs for 110826 post records belonging to 227 reblog trees ([www.communicatingchronicpain.org](http://www.communicatingchronicpain.org)). In this application, each individual post determines data retrieval, and it is amended with data scraping Tumblr’s HTML code. The application obtains metadata about the post (such as the user name, the post date, the post URL) from the API call, and a ‘reblog key’, which is used to group and posts in the visualization<sup>xv</sup>. The visualization employs D3.js on the client side, and a PHP/MySQL application on the server side. It is a Javascript generated SVG image that takes shape from the connections drawn from the reblog tree, using Euler’s constant to simulate branch growth<sup>xvi</sup>. The visualization aims to rethink what counts as communication as a post reaches from a user to the next, exploring communication as an ecological process<sup>xvii</sup> by foregrounding relations which are obscured from end end



user's point of view, and using metadata to visualize reblogs associated with individual posts. To comply with Tumblr's terms and conditions, this application only scrapes Tumblr posts through public URLs.

### **What's in a pain meme?**

“It's the little things in life that count. Like pills”, reads a generic drawing depicting a woman. This meme is an iteration of ‘little things count’, a meme that circulates on the network in explanations about what it means to live with a chronic illness<sup>xviii</sup>. In January 2014, I post this version so I can observe how users interact with it. Over two years, it accrued 274 notes. Memes like this make up Tumblr's ‘spoonie’ culture. ‘Users here’, a post remarks, ‘live by spoon theory’<sup>xix</sup>, an emic explanation of the everyday energy ‘cost’ of chronic illness originally formulated by Christine Mesarandino<sup>xx</sup>. Living with a chronic illness means one has a limited amount of spoons (units of energy) which have to be carefully administered daily, or a shortage of spoons will make one ‘crash’, bring back a flare, or intensify pain. Every activity ‘costs’ spoons, and spoon counts vary ‘from spoonie to spoonie’, across conditions, in cycles of flare and remittance, and depending on the stress toll of everyday demands. The spoon theory explains chronic pain visually to people who don't live in pain. ‘Spoonies’ often associate this identity with isolation and epistemic dissonance in everyday life, because often the way they see their illness is not how it is seen by others. Spoonies often report that people in their caring and support networks get tired of hearing about pain that does not eventually resolve, that their ‘lack of spoons’ to go on social activities is misunderstood as disinterest, and that people do not understand their inability to perform tasks others would not even consider taxing<sup>xxi</sup>. In many posts, bloggers imagine the Tumblr platform as a safe environment where others with like problems recognize what living with chronic pain looks and feels like. Many descriptions highlight that people have taken to the network because on Tumblr new forms of affective engagement with technology generate a different sense of time, agency, creativity and belonging, though users are not impervious to how communication technologies also bring about new cleavages and new forms of inclusion and exclusion (cf. Ginsburg 2012; boyd 2014; Goggin and Newell 2003).

On Tumblr, the experience of illness is predominantly expressed through images, partially connected images, that reframe pain through out of context references to visual and popular culture. Images are either tropes of pain, representing qualities of pain metaphorically through an array of representational frameworks, or the experience of relating to pain. These images share many common elements. A visual thematic analysis of 562 posts that circulated between May 2013 and March 2015 revealed a wide range of metaphoric descriptions of chronic pain experience, but only two first order themes, the difficulty of communicating about pain with clinicians and significant

others and the difficulty of coping with the effects of this (ex)communication. These images use pain metaphors alongside descriptions of social relations that depict everyday social interactions along with feelings associated not with visions of the self in pain, but with the everyday use of prescription medications and other (bio)technologies as coping mechanisms. When pain is described explicitly, memes emphasize the intensity and immediacy of pain (fig), and use referents and figurations that highlight a sense of dwelling inside pain experience, of owning pain, as well as the sense of being ‘overcome’ by pain. Pain thus becomes an experience very often described in terms of what it forecloses, rather than sensations it produces in the body. Many memes elaborate recurrent themes of being ‘stuck’ in pain<sup>xxii</sup>, ‘lost’ or incommunicated<sup>xxiii</sup>, and on the idea that being overcome by pain is like being ‘out of control’<sup>xxiv</sup>. For example, Figures 1, 2 and 3 depict migraines, using a picture frame showing an empty landscape, a fire and a textual description as representational frames.



*Figure 1 Migraine art, posted by thehec*



*Figure 2 Migraine / headache posted by migrainediscussions*



Figure 3 Migraine meme, posted by migraineblog

In the migraine figurations, the particular substitutions offered as tropes of migraine synthesise meanings and offer images that conjure up multiple stances. Tropes foreground multiple meanings, *kinds* of pain and ways of living with pain, over a single construction of the self in pain. Wagner (2012a) associates figure-ground reversals to the idea of expersonation: that a body does not necessarily precede its image but itself becomes an image, a representation in a broader narrative, as a condition of pragmatic embodiment. Unlike language, which ‘does’ things performatively and disguises its limits ‘by merging with its own perception’, tropes operate by conjuring around themselves *kinds* of agency pertaining to the phenomenon they depict (Wagner 2011:5). The sense they might refer to the concept of ‘migraine’ depends more on context the more abstract the trope. Indeed, it is images themselves, rather than a preceding meaning of migraine, that foreground migraine as a processual experience by the substitutions and metamorphoses migraine memes undergo as they circulate in the network. Migraine memes, like other chronic pain memes, make sense as series, through the relationships they establish with each other, which at once returns to and negates univocal meaning of illness, but become the vehicle through which meaning is construed.

### **#chronicpain, #chronicillness, #spoonieproblems: making chronic media worlds**

Chronic illness memes such as the chronic illness cat, the ehlers danlos zebra, or the chronic illness pots, think, feel, behave and react like would a person with a chronic illness. These memes frame clinical relations and illness frameworks through distance created through humour and figuration. Figures 5, 6 and 7 illustrate, in a general tone, how experiencing chronic pain reverses the ‘normal world’, evincing the paradoxical position that a person living with chronic pain often inhabits. The memes themselves often explicitly represent this inversion. They raise problems a person living with pain might face dealing with a diagnosis, or with insufficient medical care, or the

contradictions arising from living with with a string of co-occurring conditions and medication side effects which could be deemed irrelevant in clinical relations<sup>xxv</sup>. But to a network of people ‘in the know’, these inversions are more than liminal moments where everyday roles are ritually reversed (Babcock 1978; Turner 1985). They are a systematic commentary on the form of the everyday social and power relationships that frame pain. By reframing issues out of their normative representational frames, these memes make explicit the epistemic assumptions that produce stigmatized chronic pain behaviors. Memes enclose and disclose, reify and reveal by adding an aesthetic dimension which invests the figuration process with political value<sup>xxvi</sup>.



*Figure 5 #spoonieproblems*



*Figure 6 #chronicallyawesome*



Figure 7 #chronicpain, #chronicillness #spoonieproblems

Against intense and unpredictable cycles of recurrence and remittance, of lack of sleep, and the constant presence of pain, multiple issues emerge as individuals reclaim agency, becoming 'illness warriors', and participating in a shared imagined community. Bloggers seek to find a space not only to communicate about pain illness, but to find relief. Users seek others' identification with their experience of illness<sup>xxvii</sup>. By their admission, many seek and find 'a family'<sup>xxviii</sup>, a place where others will listen, a somewhere one can turn to even when other social worlds might be unavailable due to the often random, persistent and unpredictable temporalities of pain. A key theme in these series are encounters where clinicians, carers or significant others refuse to listen, and address a person in pain demeaning their capacity to *know* pain. Variations of the meme 'trust me, I know' illustrate this. Taking mostly a humorous stance, these memes draw on encounters where an outsider (an acquaintance, a co-worker, or a doctor who refuses to recognize the symptoms of a chronic condition and does not offer support or a diagnosis) downplays the capacity of a person in pain to know their symptoms or their best course of action<sup>xxix</sup>. Memes about alternative painscales also capture this. Whereas the visual analog scale measures pain unidimensionally, people living with pain constantly reinterpret this scale, reframing pain in affective and personal keys, and unapologetically reporting social over physical aspects of pain that are often unacknowledged in clinical pain assessments<sup>xxx</sup>.

The public nature of the social media platform enables bloggers to speak about chronic illness in their own language (cf. Ginsburg 2012), through and against mainstream pain frameworks. The socio-technical temporalities of the social network are particularly relevant to the way issues emerge and evolve within it, since posts reflect 'accidental' processes in everyday life that frame how and why meanings are shared, the kinds of tropes and agencies that become relevant to them, and that determine posting frequencies. Hospital visits, everyday pills and medication, memories, experiences and affects fuel senses of (un)belonging in the network. In this sense, the social network can become a site of transformation by bringing into experience the value of imagination to remake pain worlds. On one hand, network dynamics make communication processes

political, in the sense that communication operates, as Freeman (2010) suggests, through temporal manipulations that not only repeat, enforce and respond to particular cultural regimes<sup>xxx</sup>, but that act as a form of regulation that links bodies to other bodies, and to pre-existing cultural narratives. On the other hand, this particular mode of relational, memetic communication opens up new world-making capacities of the social network, which, reversing the conditions of everyday pain representation, and foregrounding social relations, public engagement and issue-making as central social aspects of media. Thus in the process of marking the present time, the network also brings into experience the ‘near future’, as defined by Guyer, ‘the reach of thought and imagination, of planning and hoping, of tracing out mutual influences, of engaging in struggles for specific goals, in short, of the process of implicating oneself in the ongoing life of the social and material world’ (Guyer 2007: 409)<sup>xxxii</sup>.

## **Coda**

This article explored how media networks make chronic pain matter by reimagining pain through and against biomedical frames and definitions, and articulating new collective issues around the circulation of new media representations. I argued that these temporalities reflect relations between users, technologies and protocols, but also on the way in which users imagine health communication on social media to explore aspects of illness experience that are difficult to communicate in other contexts and to make inhabitable media worlds. Tumblr users creatively participate in framing the shortcomings of healthcare provision and services, social norms and exclusions that affect people living with persistent, non life threatening chronic conditions. Health communication in social media is a response to the experience of living with pain, a way of coping with its debilitating effects, while at the same time it can be a potentially transformative act in bringing together issues and publics.

These findings have implications to open up research agendas, as Rapp and Ginsburg (2013) have suggested, from a focus on the incommensurability and incommunicability of pain to the making of pain worlds. Chronic pain communication on Tumblr highlights the gap between the acuteness of clinical pain frameworks, and their modes of assessing pain prevalence and intensity, and the experience of chronic pain as a ‘fluid state’ (Manderson and Smith-Morris 2010), one which both reflects and diffracts cultural narratives of identity, illness and debility.

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<sup>i</sup> See the Delphi report by Neeta Kumar, accessible at [http://www.who.int/medicines/areas/quality\\_safety/delphi\\_study\\_pain\\_guidelines.pdf](http://www.who.int/medicines/areas/quality_safety/delphi_study_pain_guidelines.pdf), accessed March 2015.

<sup>ii</sup> Note that most current clinical pain protocols use a form of Numerical Rating Scale (NRS) or Visual Analogue Scale (VAS) to assess pain experience. Melzack remarked in an interview with Mark Shainblum that the radically subjective nature of pain can be understood as a gateway into subjective constructions of the world (see <http://publications.mcgill.ca/headway/magazine/the-king-of-understanding-pain-qa-with-ronald-melzack/>, accessed March 2015).

<sup>iii</sup> For Scarry, pain's resistance to language is intrinsic to its ontological status, the condition of its existence, which requires 'the shattering of language' (1985: 5).

<sup>iv</sup> For example, in conditions where either the experience of pain or painfulness are absent, such as pain asymbolia or the somatization of social or emotional pain.

<sup>v</sup> As Rose and Abi-Rached (2013) and Das (2015) have noted, historical, social and cultural processes might be relevant to framing pain experience not only as a human pathology, but through the constitution of scientific categories, models and theories.

<sup>vi</sup> Carel and Kidd report that the UK Patients association lists communication as one of the top four most frequent complaints. Patient 'voice' is understood as key to improving patient experience by multiple international patients' advocacy associations (see [www.iapo.org.uk](http://www.iapo.org.uk))

<sup>vii</sup> This argument is consistent with approaches in the biosciences that favor modular theories of pain, emphasizing 'gate control' over localization specificity. Localizationist theories were developed from Descartes' description of the role of the nervous system as a mediator of the perceptual experience of pain, particularly in terms of a mechanistic explanation of physical function that portrays pain action as proportional to the extent of tissue damage (Descartes 1972: 37). In contrast, the gate control theory developed by Melzack and Wall (1965), emphasizes transmission and the role of the spinal chord as determinants of the quality and intensity of pain (Moayed and Davis 2013)

<sup>viii</sup> These political capacities have also been suggested by researchers working on other forms of digital health communication (Page 2012, Ziebland and Wyke 2012)

<sup>ix</sup> For example, a hashtag search #pain, returns 4,812,120 tagged photographs on Instagram.

<sup>x</sup> See, for instance, Lupton (2014), Sosnowy (2004), Ressler et al (2012), Mazanderani et al (2012), Mazanderani and Papparini (2015), Page (2012).

<sup>xi</sup> See Tim Wu's feature and interview with David Karp for the New York times Magazine (September 2013), [http://tmagazine.blogs.nytimes.com/2013/09/11/david-karp-is-tumblrs-reluctant-technologist/?\\_r=0](http://tmagazine.blogs.nytimes.com/2013/09/11/david-karp-is-tumblrs-reluctant-technologist/?_r=0) (accessed October 2013).

<sup>xii</sup> According to GobaWebIndex's Q3 2014 quarterly report, Tumblr became the fastest growing social network in 2014, increasing its user base by 120%.

<sup>xiii</sup> For example, a community of users around disordered eating may use the platform to promote a disordered eating lifestyle, or distorted visions of self harm can be made to look attractive through artistic images.

<sup>xiv</sup> For Wagner, images carry a synthetic meaning that reflects the social structure and, reciprocally, transpires to the social structure 'the properties of image itself, elicitation and containment' (2012b).

<sup>xv</sup> This method, while useful for illustrative purposes, is not ideal, since it would not survive changes in Tumblr's front end, and as a general rule it would not be supported by Tumblr's terms and conditions, although Tumblr staff granted us permission scrape sample posts for the purposes of this project. Tumblr

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also granted us permission to build a local cache to drive the visualization, although this would also constitute a violation their terms and conditions in principle.

<sup>xvi</sup> This function, which is often used in studying non-linear increase or decrease, such as growth or decay, is defined by differential relations.

<sup>xvii</sup> Our team was inspired by Deleuze and Guattari's discussion of the distinction between the arborified and the rhizomatic, as much as we were by debates in neuroscience about the role of the brain in pain modulation. Deleuze and Guattari build their discussion of consolidation around the distinction between dynamics of folding-in of the arborified and the branching-out of the rhizomatic. For Deleuze and Guattari, whereas the arborified is rooted and produces form from the outside in; the rhizomatic, as Buchanan (2005:40) highlights, is driven by bundles of relations from that expand from the inside out, like neural networks, by virtue of release or inhibition.

<sup>xviii</sup> See, for instance, <http://chronicillnessmemes.tumblr.com/post/106048004965/when-my-brothers-save-me-from-doing-dishes-or>, accessed January 2015)

<sup>xix</sup> See <http://alliehalfie.tumblr.com/post/115007629886/what-is-spoons> (accessed April 2015)

<sup>xx</sup> Mesarandino was explaining to her good friend what it felt like to live with Lupus when she formulated this theory. See <http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>.

<sup>xxi</sup> For example, <http://mylifewithhms.tumblr.com/post/113468882777/when-i-have-to-choose-between-something-i-want-to>, <http://boopmcrantypants.tumblr.com/post/114860868286/when-you-run-out-of-spoons-but-you-dont-want-to>.

<sup>xxii</sup> See <http://fullofdark.tumblr.com/post/82943759791> (accessed March 2015).

<sup>xxiii</sup> See <http://cripples-r-us-sweg.tumblr.com/post/113229654935/one-of-the-most-distressing-things-about-being> (accessed March 2015).

<sup>xxiv</sup> See, for example, <http://oaken-glynn.tumblr.com/post/82519535646/current-health-status> (accessed March 2015).

<sup>xxv</sup> Example posts: <http://ehlersdanloszebra.tumblr.com/post/117253564962/i-have-my-first-appointment-with-a-cardiologist-in>, <http://chronic-illness-cat.tumblr.com/post/117222689518/from-the-amazing-threateningperson9924-tumblr-com> (accessed April 2015).

<sup>xxvi</sup> Kockelman argues that it is on this basis that framing can be thought as a political activity, since 'framing may always creatively refigure, and thereby potentially obviate, the relations presupposed by any particular frame (and thus the reifications such relations are otherwise subject to)' (2013:25)

<sup>xxvii</sup> For example, a post reads: 'If you are a spoonie, please reblog, I want to gain new spoonie friends, so I don't feel alone'. At time of access - January 2015- , 496 users had reblogged this post, with many adding verbal notes describing similar experiences.

<sup>xxviii</sup> For instance, <http://communicatingchronicpain.tumblr.com/post/118110623038/spoonie-army>, <http://frenchiechronie.tumblr.com/post/98048490890/i-know-you-are-not-okay-but-i-know-you-fight> (Accessed March 2015).

<sup>xxix</sup> See, for instance, <http://milliebooboo.tumblr.com/post/61166403230>, <http://fibrozombie.tumblr.com/post/70047829695/fibro-fibromyalgia-chronic-chronicpain>, <http://heresthethingaboutit.tumblr.com/post/70372918203/and-here-ends-another-day>, <http://communicatingchronicpain.tumblr.com/post/115218210448>, <http://kayleighkavanagh.tumblr.com/post/77588637686/pickyourheartupoffthefloor-heatherbat> (Accessed March 2015)

<sup>xxx</sup> See, for example, <http://melissablanks.tumblr.com/post/33773613509/oh-lawd-pain-painscale-hospital>, <http://diariesofabuggygirl.tumblr.com/post/110146965589/feministingforchange-beatricebiologist-how-are>, <http://talledschick.tumblr.com/post/95202693892/just-the-kind-of-damn-morning-i-need-on-a-day-I>, or <http://theagliophobe.tumblr.com/post/68584238711/so-true> (Accessed March 2015).

<sup>xxxi</sup> 'This process', writes Freeman, 'extends beyond individual anatomies to encompass the management of entire populations: people whose individual bodies are synchronized not only with one another but also with larger temporal schemae experience belonging itself as natural' (2010:4).

<sup>xxxii</sup> That-fibro-life posted: 'I have the best followers... seriously. If I ever get ridiculously rich, I am building us a huge mansion that everyone and their pets are allowed to live in. It will have private doctors so we can all rest and get proper medical attention'.