

Elena Gonzalez-Polledo, [Jen Tarr](#)

## The thing about pain: the remaking of illness narratives in chronic pain expressions on social media

**Article (Accepted version)  
(Refereed)**

**Original citation:**

Gonzalez-Polledo, Elena and Tarr, Jen (2014) *The thing about pain: the remaking of illness narratives in chronic pain expressions on social media*. [New Media & Society](#), online. pp. 1-19. ISSN 1461-4448 (In Press)

DOI: [10.1177/1461444814560126](https://doi.org/10.1177/1461444814560126)

© 2014 The Authors

This version available at: <http://eprints.lse.ac.uk/60247/>

Available in LSE Research Online: November 2014

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (<http://eprints.lse.ac.uk>) of the LSE Research Online website.

This document is the author's final accepted version of the journal article. There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

The thing about pain: The remaking of illness narratives in chronic pain expressions on social media

**Abstract:** In this paper we analyse chronic pain narratives on Flickr and Tumblr. We focus on how, by incorporating visual and multimodal elements, chronic pain expressions in social media significantly extend and challenge the logic, function and effects of traditional ‘illness narratives’. We examine a sample of images and blogs related to chronic pain and formulate a typology of chronic pain expressions on these sites. Flickr brings a form of narrative immediacy, making the pain experience visible, eliciting empathy, and marking chronicity. Tumblr lends itself to more networked forms of interaction through the circulation of multimodal memes, and support communities are built through humour and social criticism. We argue that new forms of mediation and social media dynamics transform pain narratives. This has implications for our understandings of the forms and formats of pain communication and offers new possibilities for communicating pain within and beyond clinical contexts.

**Keywords:** chronic pain; narrative; Flickr; Tumblr; visual; multimodal; social media; illness

Lead Author: Elena Gonzalez-Polledo, London School of Economics and Political Science, UK.

[e.gonzalez-polledo@lse.ac.uk](mailto:e.gonzalez-polledo@lse.ac.uk).

Author biography: Elena Gonzalez-Polledo is Course Tutor in the Department of Methodology at the London School of Economics and Political Science. Her research on chronic pain focuses on exploring the relation between forms of knowledge and experience through digital, visual and ethnographic methodologies.

Author: Jen Tarr

Author biography: Jen Tarr is Assistant Professor of Research Methodology in the Department of Methodology at the London School of Economics and Political Science, and has research interests in qualitative methodology (particularly visual and other sensory methods) and the sociology of health, especially chronic pain. Together with departmental colleagues, she and Elena have recently completed the *Communicating Chronic Pain: Interdisciplinary Strategies for Non-Textual Data* project from which this article emerges ([www.communicatingchronicpain.org](http://www.communicatingchronicpain.org)). Her book *Sensory Methods in Social Research* will be published by SAGE in 2016.

“That's the thing about pain," Augustus said, and then glanced back at me. "It demands to be felt"—

**John Green, *The Fault in Our Stars***

## **Introduction**

This paper explores forms of chronic pain communication on social media platforms. Abundant research on the chasm between patients and doctors in the clinical management of chronic pain (Eccleston et al, 1997; Kugelmann, 1999; Hadjistavropoulos and Craig, 2002; Kenny 2004; Smith et al 2006; Sullivan et al 2006a; Sullivan et al 2006b; McCrystal et al, 2011), highlights that pain communication in clinical contexts is often fraught by differences in expectations and outcomes. Since there is no objective way to measure pain, the clinical relations that construe and legitimate it have even greater saliency than in other chronic conditions. While measures such as the McGill Pain Questionnaire (Melzack, 1975) or the Visual Analogue Scale (VAS) (Price et al 1983) attempt to bring objective measurements of quantity and quality to bear on pain experience, some elements always elide standardised clinical measures. Yet despite widespread recognition that pain is multidimensional, most standard instruments in clinical trials, such as the VAS or Numerical Rating Scale (NRS) measure only intensity (Lichter-Kelly et al, 2007) and thereby oversimplify and flatten dimensions such as time, quality, impact and personal meaning (Ho et al, 1996: 427). Ho et al also note that health care workers routinely underestimate pain and that patient self-reporting is the most reliable measure. As such, it is worth paying attention to how people with pain express their condition, not only through words in a clinical context, but also through other media and to other audiences.

Chronic pain expressions in social media are becoming a growing archive that can be accessed from anywhere in the world (Ernst and Parikka 2013). This archive conveys multiple experiences of what

it means to live with pain and brings them to the public domain. Focusing on the new roles of social media in the emergence of new forms of pain expression and new patterns of ‘produsage’ (Bruns, 2008), we argue that new mediated chronic pain narratives are transforming traditional models of illness experience. Studies of pain expression through photography, such as Padfield’s (2003, 2011), and of disability in the digital age (Ginsburg, 2012), attest to how the creative process involved in communicating about pain through multiple media has the potential to transform the experience of pain by shifting its locus from within to outside the body. Other studies have also demonstrated that in the process of sharing pain experiences and meanings, and engaging new dynamics that produce new caring and support relations, new forms of patient expertise emerge through communicating about chronic illness online (Ziebland, 2004).

Our contribution explores pain communication on two social media networks: Flickr and Tumblr. The paper reviews relevant literature on illness narratives and social media, and discusses the differences that shape narrative expression on these two networks. We then explore how Flickr and Tumblr each expose different dynamics of communication, following Galloway (2014).

## **Illness Narratives**

In the social sciences, the experience of pain and illness has been primarily analysed through a narrative paradigm. In particular, illness narratives are co-authored by patients and doctors in the clinical process of understanding the aetiology and prognosis of pain and have been understood as key forms of communication through which people in pain make sense of the complexity of the illness experience and possibilities of healing (Kleinman 1988, 1995). Hurwitz, Greenhalgh and Skultans (2004) define illness narratives as polymorphous, malleable and dynamic devices through which pain and illness are known and communicated in clinical contexts and beyond. These authors

highlight the role of narrative in shaping illness experience, implicating narrative's structural elements, conditions and functions in the link between illness and subjectivity (Williams, 1984; Mattingly and Garro, 2000), linking particular forms of illness expression to cultural senses of subjectivity and identity (see also Jackson, 2005; Aldrich and Eccleston, 2000; Skultans, 2007).

These approaches to illness narratives draw on structural and sociolinguistic approaches in narrative theory. However they have fallen short of addressing the complexity of pain experience and expression, because, although illness narratives often derive functionality from their analytical use in clinical and caring relations (Frank, 1995; Bury, 2001), they collapse multiple temporal, social, psychological, physical and emotional dimensions of pain. Experiences like pain often also fall outside the ability of narrative to adequately account for them.

For Frank, illness narratives are divided into restitution narratives, chaos narratives, and quest narratives. Unlike restitution and quest narratives which reproduce standard narrative structures, chaos narratives are always on the borders of language: '[chaos is] the hole in the narrative that cannot be filled in, or to use Lacan's metaphor, cannot be sutured. The story traces the edges of a wound that can only be told around... those who are truly *living* in chaos cannot tell it in words' (1995: 98). It is an anti-narrative, one that defies writing or telling. Chaos narratives relate to what Galloway et al (2014) term 'excommunication', a type of mediation that stands outside the communicative act, saying 'there will be no more messages.' This 'does not simply destroy communication, but evokes the *impossibility* of communication, the *insufficiency* of communication as a model. In this way, excommunication is prior to the very possibility of communication' (2014: 16).

Chronic pain, as an experience that actively resists language (Scarry, 1985), is an excellent example of excommunication. Writing about ‘total pain’ in the context of a sociological project on transnational dying, Gunaratnam (2013) situates pain at the borders of symbolization where the boundaries between experience and expression dissolve, and material, cultural and structural dimensions of pain experience collapse. One of Gunaratnam’s examples is the story of Maxine, a retired auxiliary nurse and hospice patient who refused to accept palliative care. Thinking with Maxine’s story, Gunaratnam argues that generating new possibilities and approaches to pain should not end in semiotic expansion or retrieval of a lost pain object. Rather, ‘it is attentiveness to the singularities of [Maxine’s] situation that can produce shifts in what we think of as pain, so that the content of our experienced world expands’ (2013:143). Despite fully recognizing the untranslatability of some aspects of pain experience, Gunaratnam recognises the unintelligible and undecidable in stories of pain, opening up a range of meanings and new opportunities for methodological exploration.

### **Illness narratives in social media**

As the field of narrative medicine expanded in the last decade (Charon and Montello, 2002, Charon, 2006, Jurecic, 2012), story-making gained a central role in defining the method and purpose of the social science of health and medicine (Hyden, 1997; Hyden and Brockmeier, 2008; Charteris-Black and Seale, 2010). Yet what counts as a narrative or story is changing. Payley (2009) argues that narratives can be placed on a continuum of high and low narrativity (a ‘narrativity ladder’). A narrative must contain more than one event; make claims about causal connection; and have a central character. To progress to the ‘high narrativity’ of a story, it must also have an ending which is prefigured by earlier events. Simpler low narrativity expressions can also be understood as narratives if they have the elements above.

Narrative theorists have long questioned how and to what effect expressions that defy traditional notions of medium can be considered narratives (Hayles 2008; 2012; Grishakova and Ryan 2010). Ryan (2010) develops the concept of intermediality by looking at non-digital media, arguing that while verbal language remains the most powerful mode of signification and representation, it has traditionally relied on non-verbal communicative forms such as sound, gestures and facial expressions, which add pragmatic and cognitive dimensions to the narrativity of a story, and which extend narrativity to images, painting, architecture and music. Page's empirical analysis of blogging (2012, see also Page and Thomas 2012), and her discussion of interactivity in the context of digital narratives, use structural and sociolinguistic paradigms in narratology to analyse online communication, demanding an examination of the reader's relation not only with the content of a story, but with the digital interface, as well as a wider range of other storytelling participants and audience members (2012:214).

### **Flickr and Tumblr: Key Differences**

In social media, chronic pain expressions are framed by the coming together of technologies, user networks and practices (Licoppe 2003). Our analysis finds that although social media has structures equivalent to traditional illness narratives; in each platform different meanings develop in relation to the medium used (text, images, multimodal content), and in relation to the social context of communication.



Flickr is designed around the photostream (van Dijck 2011) where users produce original content which they may tag, organise in sets, or add to groups. What becomes visible about chronic pain on Flickr depends on how one accesses the images: as part of a photostream, they will appear in the order they were uploaded, while as part of a user's sets they can be ordered in whatever way the user chooses. Sets allow users to stream images into a narrative structure. However not all images are part of sets, and sets are not the only way to find or view images. Flickr's homepage streams both 'interesting' images which have been Favourited often, and 'most recent' images (van Dijck 2011: 409; Lee et al 2010). Tagging images makes them searchable by keyword, meaning they may be encountered out of context, near other images with the same tag. Users are likely to encounter each other's images individually rather than as part of sets, particularly if a user is searching the Flickr database rather than looking through sets of a specific user. It is also possible for users to curate other users' images into a 'gallery' of up to eighteen images, so that images can be used to tell a story not envisioned by their creators. However in both groups and galleries, the identity of the image's creator is preserved by inclusion of usernames.

Tumblelogs are made of content which is often ambiguous, fragmented and multimodal. The Tumblr stream interface, however, facilitates dynamics of appropriation, mimesis and repetition that link users through the interface's main functions (reblogs and likes), and sometimes through the addition of text notes to content. The key content type in Tumblr are memes, which often depict variations of humorous everyday descriptions of chronic pain experiences (Shifman 2013; Blackmore 1999). Chronic pain memes often deploy a range of chronic pain messages over gifs or animated scenes depicting popular film and television scenes. Simple talking memes describe everyday encounters, meanings and implications of living with chronic pain or with a particular chronic illness. Alongside their explanatory value, they circulate in a network that provides support for users (who often remark on the social support received). But although many of these characteristics have been found

to be central in other social media (Dean 2010, Berry et al 2010, Ito 2010), Tumblr uniquely draws on abstract depersonalised expressions built on provocation, humour and sarcasm. The process of real-time transmission shifts the centrality of individual profiles to networks of content where ‘imitation and remixing become the pillars of participation’ (Shifman 2013). Here the platform’s architectural affordances, in suggesting the types of content that can be uploaded, and the types of interactions allowed (adding text notes, liking and reblogging) both suggest and limit possibilities of interaction (Papacharissi 2011).

## **Method**

### *Sampling*

The challenge for qualitative researchers working on social media data is to select from large quantities of relevant content to conduct in-depth analysis of a manageable number. Due to inconsistencies in the amount and authenticity of user information and anonymous content posted online, we have not tried to triangulate chronic pain expressions with users’ demographic characteristics. We include a range of conditions as well as undiagnosed causes of chronic pain, including people with fibromyalgia, back pain, migraine, Ehlers Danlos syndrome, multiple sclerosis, lupus, musculoskeletal and other conditions, some diagnosed and some unclassifiable. Although conditions such as depression are often an inseparable part of living with chronic pain, we have not selected material where the pain expression seemed to be predominantly about emotional pain. This is not to say that we were unaffected by the material: after sifting through so much content related to pain it was difficult not to feel moved by what users had shared and to feel more heavily the weight of responsibility for representing them fairly.

On Flickr, we conducted a search for images tagged with ‘chronic pain.’ The photostreams of users who adopted that tag were searched for similar terms, such as ‘pain’, ‘hurt’, or specific ailments (e.g. ‘migraine’, ‘arthritis’, ‘fibromyalgia’). We also identified and joined two groups specifically devoted to images around pain. The first group, ‘Show Me Your Pain’ collected nearly 400 targeted images on chronic pain, while the second, ‘The Art of Pain’ was more diffuse, with over 3000 images, many only obliquely related to chronic pain. In total we looked through around 6000 images. Of these, 133 were selected and added to our Favorites, based on the following criteria: they were attributable to an individual user; they were non-commercial and not intended to advertise anything; and the person who produced them was referring to their own pain, as indicated by the photo description or information from the user’s public profile. Images were further selected according to qualitative research principles of ‘theoretical saturation’ (Glaser & Strauss, 1968) to extend range and depth, to include the widest possible variety of representations. Images were predominantly digital photographs but also included drawings and collages made by hand or with graphics software. We then devised a typology from amongst the images in our Favorites.

On Tumblr we selected 110 blog posts out of the stream of the 749 chronic pain related blogs we follow from an account that openly stated our research intentions. The blogs we follow share a defining characteristic: their authors present their profiles and/or blogs as being related to chronic pain, defined often through a ‘series’ of conditions, symptoms and attitudes that condense their experience. We surveyed real time dynamics on the network each day for over eight months, and our analytic strategy aimed to capture posts in all content categories outlined, and for a period of six months we ‘followed’ these posts noting particularly user interaction.

### *Ethics*

While uploading content to social media does not necessarily indicate consent to have it included in a research project, several characteristics made the data public. We selected public tagged content as this suggests users want it to be searchable. Within each site we set up a profile, describing our work and linking to our website. Images from Flickr are used in accordance with Creative Commons licencing. Memes are meant to travel and be shared virally and it is often impossible to trace their origin, so these have been captured at one stage in their journey, and quoted within permalinks where they are embedded within the blogs where we encountered them.

### *Analysis*

We paid particular attention to recurrent patterns expressed on each website with the aim of identifying similarities and differences between various forms of content and themes contained therein, as well as the relationship between users, content and the whole. Although we viewed the comments and titles images and memes, we have not analysed these. Our aim was to systematically classify visual and multimodal expressions of pain without losing the distinctiveness of the experiences conveyed by social media users. The analytic framework emerged from repeated engagement with the items identified for analysis and in the case of Tumblr, tracing of patterns of circulation. To account for the multiple scales, media, temporalities and functions that link narrative to pain, we propose to analyse chronic pain expressions in social media through a tripartite framework encompassing elements of narrative theory and visual analysis and social media analysis.

We draw elements from narrative analysis in health care to contextualize the logics, contexts, functions and forms (Eva, 2009; Frank, 2010) of chronic pain expressions in social media. The illness narrative framework has weaknesses in relation to understanding expressions on social media however: its proponents still work with a concept of a coherent, language based narrative articulated

by an individual, which provides a unique hermeneutic and functional context. Yet the expressions we analyse differ in that their scope and functionality are derived from engaging multiple technologies, audiences and interpretations during their lifetime.

As a form of social media analysis, we draw on Galloway (2014)'s work on changing practices of mediation, modelled through the figures of Hermes, Iris and the Furies as representatives of hermeneutics, iridescence and symptomatics, three steps in communication, each a succession to and evolution of the previous. Flickr shares some characteristics with Galloway's description of immanent or 'iridescent' communication associated with the Greek messenger goddess Iris, counterpart to Hermes (2014: 46): it has immediacy, and is meant to communicate experientially rather than hermeneutically. It is often also unidirectional, as images may not be seen, commented upon, or favoured by other users, and even if they are, two-way communication does not necessarily ensue. Galloway writes that in iridescent communication, which he associates with images,, 'It is simply a question of being present at hand to tell. Once relayed, the telling is already consummated' (2014: 45). As we show, a similar dynamic is at work on Flickr.

Tumblr mirrors the 'symptomatics' mode of fragmented, dispersed and multiple communication, which no longer aims to represent or show reality. This mode of communication, as Galloway writes: 'demonstrate[s] that truth is not inside or even outside the real, but simply alongside it, nipping at its heels' (2014:61). For Galloway, these symptomatics take the shape and temporality of the Furies of mythology: a swarm, an assemblage, or a network. Furious communication does not necessarily have a single centre, but gains commonality as a system and negotiates excommunication not as a critical 'in between', but in 'massively distributed forms of communication that exceed normative –and human- forms of communication' (2014:80). Emerging from multiple and constantly reorganizing centres, communication is no longer bilateral, and resists being reduced to a model and fixed to

meaning. As systems, furies embody a nonhuman form and ‘interface directly with the paradox of communication, speaking ‘in one voice across the many different multiplicities of being’ (2014:63)

Our Flickr analysis also draws on visual analysis tools such as semiotics, in order to understand what images *do* (Kress and van Leeuwen 2006; Rose 2001). In addition to standard semiotic categories such as denotation and connotation, Jewitt and Oyama (2001) identify social semiotic elements such as the framing of an image, its composition, point of view, and salience which can frame visual semiotic analyses. Rose (2001: 16-17) similarly identifies multiple sites at which meaning is made within the image: since we know little about the production or viewing audience of Flickr images, we have focused our analysis predominantly on the image itself, taking into account the compositional features described by Jewitt and Oyama but not the more speculative features of semiotic analysis such as connotation (Barthes, 1973).

## **Discussion**

### **Flickr: Narrative Immediacy and Iridescence**

While structural elements of illness narratives persist on Flickr in sets, captions or comments, the images often stand alone, ambivalent in meaning. Flickr images seek to communicate in three ways: they *make pain visible*, by highlighting aspects of the experience of living with pain or portraying a person as being in pain; they appeal to empathy by *making pain felt*, using simile or metaphor (‘the pain is like *this*’) and/or trying to evoke the pain viscerally; or they *make chronicity visible*, by building a sequence of images around pain, often through 365 projects, photo journals in which people take and upload one photo every day for a year. This last aim is most similar in structure to offline and text-based narratives.

The semiotics of images made by people with pain are striking. They tend to use black and white, and a sparing use of colour to highlight areas of pain. Red is the most common colour used, followed by blue. There is a tendency to over- or under-exposed images, as well as the use of blur and effects of Photoshop or PhotoBooth software to render images with grainy, cracked or rippled surfaces. Common visual signs, including similarities in ‘references, forms, colour and metaphor’ were also noticed by Padfield in her work creating photographs with people with pain; suggesting ‘a generic iconography for pain’ (2011:249) of which these are elements. Many of her images (2003) are also in dark tones with textures and spots of bright colour.

Images aiming to make pain visible are often self-portraits, with facial expressions used to convey the experience of pain. These are frequently black and white or low contrast images. Those focused prominently on the head often refer in the title or caption to migraine as the source of pain.

Grimaces or silent cries are common in these images, as is the gesture of holding the head. Aside from migraines, images from people with other kinds of pain show bodies that are contorted, prone, or vulnerable, again often in black and white or muted tones. In some, the semi-nude body is balled up, only the spine visible, as if blocking off the more vulnerable chest and face, or images are framed to fragment of the body itself, with the painful part abstracted from the rest of the body, suggesting ambivalence and/or disinvestment in it. It is rare to see the whole body.

Other images show material aspects of a sufferer’s daily life, making these visible. These may have to do with medication, and pictures showing the number of pills taken are common. Unlike pain, medication has visibility, and the quantity of pills shows some objective recognition of the pain.

While the person may not ‘look sick’, as users note, medication is a material reality of their suffering and stands for the effort that goes on ‘behind the scenes’. In contrast to images of people with pain, pills are often brightly contrasting and stand out against the background. This partly plays on

iconography of ‘taking pills like candy’ where the medication is framed to appear abundant and appealing.

Images where the aim is to make pain felt tend to focus on modifications to the image. They are made not merely through standard photographic practices but also through image manipulation. The effect of pain is evoked through blurred edges, cracked surfaces, or the appearance of being immersed under water or wrapped in a web of gauze. Amongst migraine sufferers, images often attempt to express something of the experience of migraine itself, as well as drawing an implicit simile: the pain is *like this*. Drawings and collage images seem to be particularly common amongst migraine sufferers, who also produced abstract patterns and used more colour than other users, in part as a reference to visual disturbances experienced by many as part of migraine. These images evoke disturbance of norms, showing something outside everyday experience.

Other images attempt to illustrate what the pain feels like, suggesting the sensory experience of *having* pain. This is less about finding a source for comparison than about evoking the pain viscerally. Jilly999’s image ‘hand pain’ is an example of this. Here, an x-ray style image, the ‘objective’ measure of anatomy produced in the clinical encounter, is given a radical ‘subjective’ twist through the colouring of red and purple, electric streaks issuing out from the hand itself suggesting nerve pain, and the addition of nails stabbing into the spaces between the digits. The red colour also suggests heat or a burning sensation.





Figure 1: 'hand pain' by jilly999

Immediacy is central to Flickr. The default, photostream setting is chronologically based and loads newest images first. Van Dijck characterises it as ‘a constantly changing database that lacks even the most elementary principles of an archive’s ordering and preservation system’ (2011: 409). An ongoing series such as a 365 project allows a more sustained, less fragmented narrative structure to appear. Images may still be viewed out of context, but often reference is made to the fact that the images are part of a series; they refer to other images. What these series show is the passage of time: chronic pain and chronic illness don’t simply cause severe suffering in an instant, but are part of an extended daily struggle. For instance, in a series from a 365 project by user Snowflakesarewhite, ‘spoon theory’<sup>1</sup> is illustrated literally by showing how many ‘spoons’ (units of energy) are used during daily activities such as showering and having breakfast. The caption on the image below refers to the energy it takes to stand up in the shower, to lift her hands above her head to wash her hair, and deal with the effects of the heat and humidity. The photographer’s feet and painted toenails

contrast with the muted blue-grey of both spoons and tiles, suggesting that spoons are shed like water, down the drain.

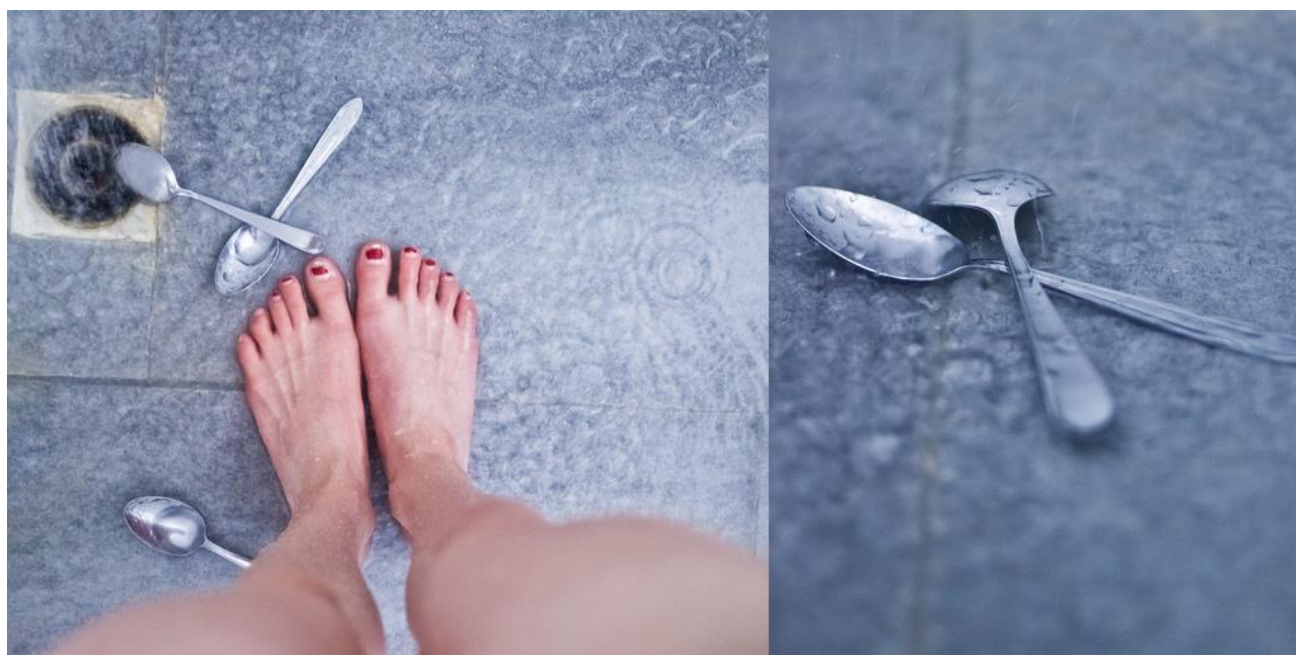


Figure 2: '216.365 8:30 AM shower' by Snowflakesarewhite

Some images appear in photostreams as a literal temporal and narrative disruption, accompanied by a comment to the effect of 'this is why I haven't been posting many photos lately', and disclosing the condition or illness causing the pain. Others are part of sets related to the experience of chronic pain or disease. Some users use Flickr primarily to document and express elements of pain and illness, but more commonly they are elements within wider projects where pain periodically shifts from background to foreground.

On Payley's narrativity ladder, individual images have low narrativity: they may contain a central character and an event but rarely more than one. Sets and 365 projects contain more than one event, fulfilling two narrative criteria, but rarely contain causal claims or relationships. Rather, following Galloway, these three types of visual pain communication are an 'iridescent' form of communication in the sense that they *appear*, and by appearing and bringing to visibility certain aspects of the pain

experience, their work is done. They maintain some elements of narrative, by documenting an event or having a central figure, but are no longer ‘illness narratives’ per se. Neither are they ‘chaotic’ in Frank’s sense, although they lack structure and are outside of words. They appeal and refer directly to experience and immediacy. A Flickr photostream is ‘fleeting, malleable, immediate, and contains a type of liveness in its initial appearance’ (Murray, 2008: 157). In Galloway’s model, iridescent communication *tells*, yet it ‘is contentless’: it is affective and illuminating, but does not interpret or discuss. Flickr users with pain do exchange comments on photos but it is not their primary form of engagement and many images receive no comments. To ‘favourite’ an image is not to engage in sustained discussion but merely to mark affective success: it has transmitted something. Although non-narrative in structure, Flickr images continue to communicate something about pain.

### **Tumblr: Narrative symptomatics**

While Flickr relies on single users where images belong to one person, narrative fragments in microblogging platforms like Tumblr are inherently relational. Every chronic pain blog we analysed brings together elements that relate to pain and chronic illness in a broad sense. In Tumblr, a social network particularly popular amongst young people, these messages are not primarily textual, nor do they necessarily share a physical or historical proximity, but rather bring together heterogeneous elements and find unconventional forms of narrativity.

Multimodal expressions offer unique features compared to text. For example, as in Flickr, we found that Tumblr bloggers upload graphic accounts that illustrate moments of pain, such as photographs of their bodies, hospital stays, taking medication or suffering side effects. These photographs fit in with a type of coping narrative that shares features with Frank’s quest narrative: they illustrate an effort to come to terms with diagnosis, and the need to reach out for support. However, Tumblelog archives

suggest that posting frequency, thematic and content types vary greatly over time. This reflects Ressler et al's study of text based illness blogs (2012), where the researchers surveyed bloggers' motivations and found that sharing the experience of illness with others (82%) and learning about illness and illness patterns to be among the top reported reasons to blog about illness. Ressler et al found that, over time, the form of bloggers' involvement shifted from the diary form to a method of advocacy, an opportunity to develop relationships of support and mentorship, a practice intended to reach out and connect, and sometimes a way to vent out frustrations and conflicts that relate to experiencing pain and disability. Tumblelog archives similarly suggest an evolution of themes in time. Over time, chronic pain related content is diluted in streams of content, dissociating expression from the temporality of an illness narrative that eventually resolves (Ricoeur, 1991; cf France et al 2013). Rather, in chronic pain tumblelogs are structured in loops of recurrent improvement and flare-up and offer temporal structures that result from fragmented temporalities; for example through the superposition of multiple conditions and the use of perception altering pain medication. These temporalities provide a new socionarratological context where chronic pain narratives perform new functions. No longer primarily oriented to accessing health services, these narratives only partially follow narrative conventions, sometimes conveying details of everyday experience through figuration, fragmentation, abstraction, metaphor or simile, but profoundly reconfiguring understandings of the function and form of narrative in significant ways. As in Flickr, many posts attempt to conceptualise or represent pain, but more often they bridge experiential worlds by developing new grammars that will trigger new social relations and associations (for instance, linking pain to aesthetic or desirable images, critically reporting about everyday frustrations by using conceptual terms, jokes or sarcastic statements). It is the social engagement that happens after content is posted (that a post is reblogged or liked) that matters, and from this standpoint we conceptualise the type of mediation in Tumblr as *symptomatics*. This mode of communication does not aim to represent reality but is rather sceptical of any essential truth as Galloway highlights,

‘reveal[ing] the structured absences, contradictions and misunderstandings’ (2014:39), ‘complicating’ any simple reading of chronic pain. Here, what matters is not the representation of chronic pain within an individual story or the negotiation of what it means between two people; rather, the circulation of multiple expressions in the system, their appropriation and resonance with other expressions raises issues beyond the exegetic or hermeneutical framework, reading for what isn’t necessarily already there, but ‘should’ be.

While in Tumblr content posted by users whom we assume are individuals is the most common, there is a host of textual content under chronic illness and chronic pain tags that refers to educational material and fundraising initiatives, offering coping or support narratives for users with specific conditions or aims to raise awareness. Yet these photographs and memes acquire new meaning as they are reblogged by users in the platform and embedded in individual profiles, and as the original content is modified with ‘notes’ or support messages that reframe the original message, adding new significance. Participants are linked within the platform by following each other’s blogs, and the material they post is variously produced, appropriated, modified and reposted by other users, to the extent that aesthetic, medium-determined and communicative patterns emerge as a result of the sharing function.

As technological mediations make visible and connect new dimensions and temporalities of living with chronic pain, we found that the more personal visual narratives, those that depict more accurately a single person’s experience, gather lower note counts than generic content that resonates with chronic pain experience. For instance, we retrieved four iterations of a meme that captures the line from John Green’s novel *The fault in our stars* (2012) with which we began this paper: ‘that’s the thing about pain: it demands to be felt’<sup>ii</sup>. The different note counts they accrued were an indication of how aesthetic expression makes relevant new relations that reconfigured and shaped the

message, raising questions around the kinds dynamics of imitation at play (Tarde and Parsons 2010; Aunger 2002). This type of referentiality may indicate that communication about pain in this network does not address a general audience, instead seeking to generate resonances with others who share the experience of pain. In fact, the difficulty of ‘fitting in’ with mainstream narratives and particularly medical discourses is often elaborated upon as a form of excommunication built on stigma, isolation and exclusion<sup>iii</sup>. In its network form, the circulation of pain expressions in Tumblr refers to chronic pain, but in doing so sceptically and with multiple simultaneous voices links to wider ‘clues’ that reveal structural contradiction, paradoxes and absences.

Among the chronic pain blogs we follow on Tumblr, memes and gifs often contain elements that put pain experience at a distance from the communicative act they perform. These posts relate to issues of inequality, discrimination and perceived lack of structural support from healthcare professionals and often offline social networks; in short, they relate to pain itself as a form of difficult communication that often fails to be negotiated, resulting in exclusion and silence. Humour and provocation become the new symptomatics of these problems, pointing to wider questions: ‘should chronic pain have politics?’<sup>iv</sup>. Memes such as the Chronic Illness Cat, which covers all forms of chronic pain, or other disease specific memes<sup>v</sup>, critically describe everyday situations of living with pain, making them matter in new ways. Often these memes are also provocations that point at the systemic shortcomings of health services and cast new light on the context, structure and conceptual limits of pain. By positing their messages outside the realm of ‘real’ chronic pain measurements and interventions, posters become witnesses whose testimony contains clues of the politics of chronic pain, the values that ‘should’ sustain the community<sup>vi</sup>. Real time interaction differentiates microblogging about chronic pain from other social networks and at the same time highlights the constitution of the social network as what boyd describes as ‘networked publics’: at once a space constructed by networked technologies and an ‘imagined community of people, technology and

practice' (2014:5). In this context, the processes of transmission, modification and transformation that users engage in while using these networks, become a crucial area of enquiry (Hartley, Burgess and Bruns 2013) that shift the centrality of individual expression to sharing, liking and reblogging dynamics, situating pain experience predominantly as a collective form.

## **Conclusion**

Where Flickr fragments illness narratives and emphasises immediacy and telling over dialogue or discourse, Tumblr further dissolves narratives through reblog functions that eliminate not only the multiple events and causal structure Payley (2009) argues are necessary for narrative, but also the main character, whose experience and story is shared rather than unique. Despite losing all the narrative structures required to sustain them as 'illness narratives' per se, both Flickr and Tumblr expressions continue to communicate something of the lived and felt experience of pain, through visual and multimodal means.

Our research reveals how digital forms of pain expression open up new possibilities of imagination, action and advocacy not bound by the dynamics and the 'rules' of offline social relations (Baym 2010). Our analysis raises new questions about the implications of social media in the making of online landscapes of pain expression, where pain can no longer be merely understood as an incommunicable substance that debilitates and hinders an individual's body and social life. Rather, pain communication is reconfigured as 'iridescent' or 'symptomatic' communication; by making aspects of the pain experience visible, or by networks of voices engaging and reinterpreting pain in networks of multimodal communications.

What develops through Tumblr, and to a lesser extent through Flickr, are ‘networked narratives’ (McNeill 2012: 78). Social media are therefore part of the act of configuring pain expression, as much as the users themselves are (Feldman 2012). To this assemblage of users and social media we should also add the materiality of pain itself, and its specific qualities and temporality: pain itself acts and enacts particular relations (Gilmore, 2012: 92) based on its qualities.

There are reasons that both pain clinicians and the general public can benefit from more in-depth engagement with chronic pain in social media (Ressler et al. 2012). Padfield et al (2010)’s survey of pain clinics found that photographic images were useful in clinical consultations, improving communication and clinicians’ understandings of patient experiences. Their set of 64 images were created together with one artist, and expansion of the range of images available through a large scale resource like Flickr could enable more patients to find visual representations of their pain to assist them in explaining its affective dimensions to clinicians. Tumblr content is often more overtly critical and political, and would perhaps be harder for many clinicians to hear. However, such content often neatly encapsulates the feelings of people with pain, and the frequency with which various expressions are reshared could provide insights into how common particular experiences are. Further, one of the problems raised by the clinical encounter is the need for brevity, and the succinct encapsulation offered by Tumblr content may help here as well.

Our primary interest however has been in chronic pain expression beyond the clinical encounter, and here Flickr and Tumblr offer opportunities for people without pain to better understand the experience of having pain. By remaking illness narratives in fragmented, immediate, and networked forms, they become, perhaps, easier for others to understand. The widespread popularity of social media also enables wider distribution of messages about pain, potentially challenging



excommunication and ableism. Social media can also enable new types and forms of networks and interactivity, effectively remaking both our understandings of pain and about illness communication.

## Notes

---

<sup>i</sup> 'Spoon theory', by blogger Christine Miserandino, has become an Internet shorthand for the experience of living with a chronic illness, having to think constantly about the number of 'spoons' as units of energy that are used up by daily activities: <http://www.butyoudontlooksick.com/wordpress/articles/written-by-christine/the-spoon-theory/>

<sup>ii</sup> See <http://cherrybam.tumblr.com/post/38751746221>, <http://hellunder-thesea.tumblr.com/post/73996169830>, <http://hellyeahjustlikethat.tumblr.com/post/75174632442>, <http://erica-san.tumblr.com/post/20251842568/thats-the-thing-about-pain>, accessed April 2014.

<sup>iii</sup> See <http://feathers-oars-blades.tumblr.com/post/85431561824/fibro-bro-happy-fibromyalgia-awareness-day>, <http://aww-tistic.tumblr.com/post/85431869324/ifihavethespoons-every-time-i-search>, or <http://spottydotty45.tumblr.com/post/81083206814>, accessed April 2014.

<sup>iv</sup> See for example three common types at <http://palewansickly.tumblr.com/post/83012413428/when-youre-filling-out-a-form-and-it-says-list-your>, <http://megsmiracles.tumblr.com/post/81846270007> and <http://communicatingchronicpain.tumblr.com/post/74855855949/via-nikki-wiser>, last accessed April 2014.

<sup>v</sup> See <http://chronicillnesscat.tumblr.com/>, <http://potsproblems.tumblr.com/>, <http://ehlersdanloszebra.tumblr.com/>, last accessed April 2014.

<sup>vi</sup> See, for example the following post <http://communicatingchronicpain.tumblr.com/post/78542474101/when-someone-makes-a-really-ableist-comment> where the poster refers to their blog as a site to denounce ableism. <sup>fin</sup>sihe <http://iwillbehealthygetfit.tumblr.com/post/84457260465>, a everyday example of response.

## Acknowledgements

This was funded by the UK's Economic and Social Research Council through the National Centre for Research Methods under the Methodological Innovations Projects scheme [Communicating Chronic Pain: Interdisciplinary Strategies for Non-Textual Data]. We acknowledge the contribution of Aude Biquelet to an earlier draft of this manuscript. We would also like to thank the anonymous reviewers for their helpful comments on previous drafts.

## References

Aldrich S and Eccleston C. (2000) Making sense of everyday pain. *Social Science & Medicine* 50: 1631-1641.

Barthes R. (1973) *Mythologies*, London: Grenada.

- Baym NK. (2010) *Personal Connections In The Digital Age*, Cambridge: Polity.
- Berry C, Kim S and Spigel L. (2010) *Electronic elsewheres: media, technology, and the experience of social space*, Minneapolis, Minn.: University of Minnesota Press.
- Blackmore SJ. (1999) *The Meme Machine*, New York: Oxford University Press.
- boyd d. (2014) *It's complicated. The social lives of networked teens*, New Haven and London: Yale University Press.
- Bruns A. (2008) *Blogs, Wikipedia, Second Life, And Beyond: From Production To Prodsusage*, New York; Oxford: Peter Lang.
- Bury M. (2001) Illness narratives: fact or fiction? *Sociology of Health and Illness* 23: 263-285.
- Charon R. (2006) *Narrative medicine: honoring the stories of illness*, New York ; Oxford: Oxford University Press.
- Charon R and Montello M. (2002) *Stories matter: the role of narrative in medical ethics*, New York ; London: Routledge.
- Charteris-Black J and Seale C. (2010) *Gender and the language of illness*, Basingstoke: Palgrave Macmillan.
- Dean J. (2010) *Blog theory: feedback and capture in the circuits of drive*, Cambridge: Polity.
- Eccleston C, De C. Williams AC and Rogers WS. (1997) Patients' and professionals' understandings of the causes of chronic pain: Blame, responsibility and identity protection. *Social Science & Medicine* 45: 699-709.
- Ernst W and Parikka J. (2013) *Digital Memory And The Archive*, Minneapolis, Minn.: University of Minnesota Press.
- Eva G. (2009) Narrative, story and service evaluation - patients' stories and their consequences. In: Gunaratnam Y and Oliviere D (eds) *Narrative and Stories in Health Care. Illness, Dying and Bereavment*. Oxford: Oxford University Press.
- Feldman Z. (2012) Simmel in cyberspace. *Information, Communication and Society* 15: 297-319.

- France EF, Hunt K, Dow C, et al. (2013) Do men's and women's accounts of surviving a stroke conform to Frank's narrative genres? *Qualitative Health Research* 23: 1649-1659.
- Frank AW. (1995) *The Wounded Storyteller: Body, Illness And Ethics*, Chicago ; London: University of Chicago Press.
- Frank AW. (2010) *Letting Stories Breathe: A Socio-Narratology*, Chicago, Ill.: University of Chicago Press.
- Galloway A. (2014) Love of the middle. In: Galloway A, Thacker E, Wark M (eds) *Excommunication: Three Enquiries in Media and Mediation*. Chicago; London: University of Chicago Press.
- Gilmore L (2012) Agency without mastery: chronic pain and posthuman life writing. *Biography* 35: 83-98.
- Ginsburg F. (2012) Disability in the digital Age. In: Horst HA and Miller D (eds) *Digital Anthropology*. Oxford: Berg.
- Glaser BG, Strauss and Strauss AL. (1968) *The Discovery Of Grounded Theory*. London: Weidenfeld & Nicolson.
- Green J. (2012) *The Fault In Our Stars*, London: Penguin Books.
- Grishakova M and Ryan M-L. (2010) *Intermediality and storytelling*, New York: De Gruyter.
- Gunaratnam Y. (2013) *Death and the migrant: bodies, borders and care*, London: Bloomsbury.
- Hadjistavropoulos T and Craig KD. (2002) A Theoretical Framework For Understanding Self-Report And Observational Measures Of Pain: A Communications Model. *Behaviour Research and Therapy* 40: 551-570.
- Hartley J, Burgess J and Bruns A. (2013) *A Companion To New Media Dynamics*, Chichester; Malden, MA: Wiley-Blackwell.
- Hayles K. (2008) *Electronic Literature: New Horizons for the Literary*, Notre Dame, Ind.: University of Notre Dame.

- Hayles K. (2012) *How we Think: Digital Media and Contemporary Technogenesis*, Chicago; London: The University of Chicago Press.
- Ho K, Spence J and Murphy M. (1997) Review of pain-measurement tools. *Annals Of Emergency Medicine* 27: 427-432.
- Hurwitz B, Greenhalgh T and Skultans V. (2004) *Narrative Research In Health And Illness*, Malden, Mass.; Oxford: BMJ Books.
- Hyden L-C. (1997) Illness and narrative. *Sociology of Health and Illness* 19: 48-69.
- Hyden L-C and Brockmeier J. (2008) *Health, illness and culture: broken narratives*, New York; London: Routledge.
- Ito M. (2010) *Hanging out, messing around, and geeking out: kids living and learning with new media*, Cambridge, Mass. ; London: MIT Press.
- Jackson JE. (2005) Stigma, liminality and chronic pain: mind-body borderlands. *American Ethnologist* 32: 332-353.
- Jewitt C and Oyama R. (2001) Visual analysis: A social semiotic approach. In: van Leeuwen T and Jewitt C (eds) *Handbook of Visual Analysis*. London and Thousand Oaks: Sage, 134-156.
- Jurecic A. (2012) *Illness as narrative*, Pittsburgh: University of Pittsburgh Press.
- Kenny DT. (2004) Constructions of chronic pain in doctor–patient relationships: bridging the communication chasm. *Patient Education and Counseling* 52: 297-305.
- Kleinman A. (1988) *The Illness Narratives: Suffering, Healing, And The Human Condition*: Basic Books.
- Kleinman A. (1995) The Social Course Of Chronic Illness: Delegitimation, Resistance And Transformation In North American And Chinese Societies. In: Toombs SK, Barnard D and Carson RA (eds) *Chronic illness: from experience to policy*. Bloomington and Indianapolis: Indiana University Press.

- Kress, G. and van Leeuwen, T. (2006) *Reading Images: The Grammar of Visual Design*, Oxford and New York: Routledge.
- Kugelmann R. (1999) Complaining about chronic pain. *Social Science & Medicine* 49: 1663-1676.
- Lee JG, Antoniadis P, Salamatian K (2010) Faving reciprocity in content sharing communities: A comparative analysis of Flickr and Twitter, *Proceedings of International Conference on Advances in Social Networks Analysis and Mining*, Odense: Denmark.
- Lichter-Kelly L, Martino S.A, Broderick J.E, et al. (2007) A Systematic review of measures used to assess chronic musculoskeletal pain in clinical and randomized controlled clinical trials. *The Journal of Pain* 8: 906-913.
- Licoppe C. (2003) 'Connected' presence: the emergence of a new repertoire for managing social relationships in a changing communication technoscape. *Environment and Planning D: Society and Space* 22: 135-156.
- Mattingly C and Garro LC. (2000) *Narrative and the cultural construction of illness and healing*, Berkeley; London: University of California Press.
- McCrystal KN, Craig KD, Versloot J, et al. (2011) Perceiving pain in others: Validation of a dual processing model. *PAIN* 152: 1083-1089.
- McNeill L (2012) There is no "I" in network: Social networking sites and posthuman auto/biography. *Biography* 35: 65-82.
- Melzack R. (1975) The McGill Pain Questionnaire: major properties and scoring methods. *PAIN* 1: 277-299.
- Murray, S. (2008) Digital images, photo sharing, and our shifting notions of everyday aesthetics. *Journal of Visual Culture*, 7(2): 147-163.
- Padfield D. (2003) *Perceptions Of Pain*, Stockport: Dewi Lewis.

- Padfield D, Janmohamed F, Zakrzewska JM, Pither C, Hurwitz B (2010) A slippery surface... can photographic images of pain improve communication in pain consultations? *International Journal of Surgery*, 8(2): 144-150.
- Padfield D. (2011) “Representing” the pain of others’, *Health* 15(3): 241-257.
- Page RE. (2012) Blogging on the body. Gender and narrative. In: Page RE and Thomas B (eds) *New Narratives. Stories and Storytelling in the Digital Age*. Lincoln and London: University of Nebraska Press.
- Page RE and Thomas B. (2012) *New narratives: stories and storytelling in the digital age*, Lincoln, Neb.: Bison.
- Papacharissi Z. (2011) Conclusion: A networked self. In: Papacharissi Z (ed) *A Networked Self: Identity, Community and Culture on Social Network Sites*. New York and London: Routledge.
- Payley J. (2009) Narrative Machinery. In: Gunaratnam Y and Oliviere D (eds) *Narrative and Stories in Health Care. Illness, Dying and Bereavment*. Oxford: Oxford University Press.
- Price DD, McGrath PA, Rafii A, Buckingham B (1983) The validation of Visual Analogue Scales as ratio scale measures for chronic and experimental pain. *Pain* 17: 45-56.
- Ressler PK, Bradshaw Y, Gualtieri L, et al. (2012) Communicating the experience of chronic pain and illness through blogging. *J Med Internet Res* 14(5): e143.
- Ricoeur P. (1991) Life in quest of narrative. In: Wood D (ed) Paul Ricoeur: *Narrative and Interpretation*. London and New York: Routledge, 20-33.
- Rose G. (2001) *Visual Methodologies: An Introduction to the Interpretation of Visual Materials*, London: Sage.
- Ryan M-L. (2010) Fiction, cognition and non-verbal media. In: Grishakova M and Ryan M-L (eds) *Intermediality and Storytelling*. New York: De Gruyter.

- Scarry E. (1985) *The body in pain: the making and unmaking of the world*, New York; Oxford: Oxford University Press.
- Shifman L. (2014) *Memes In Digital Culture*, Cambridge Mass: MIT.
- Skultans V. (2007) *Empathy And Healing: Essays In Medical And Narrative Anthropology*, New York: Berghahn Books.
- Smith MY, Winkel G, Egert J, et al. (2006) Patient-physician communication in the context of persistent pain: validation of a modified version of the patients' perceived involvement in care scale. *Journal of Pain and Symptom Management* 32: 71-81.
- Sullivan MJL, Martel MO, Tripp D, et al. (2006a) The relation between catastrophizing and the communication of pain experience. *PAIN* 122: 282-288.
- Sullivan MJL, Thibault P, Savard A, et al. (2006b) The influence of communication goals and physical demands on different dimensions of pain behavior. *PAIN* 125: 270-277.
- Tarde G and Parsons EWC. (2010) *The Laws Of Imitation*, Charleston: Bibliolife.
- Van Dijck, J. (2011) 'Flickr and the culture of connectivity: Sharing views, experiences, memories. *Memory Studies* 4(4): 401-415.
- Williams G. (1984) The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness* 6: 174-200.
- Ziebland S. (2004) The importance of being expert: the quest for cancer information on the Internet. *Social Science & Medicine* 59: 1783-1793.