

Hanging with the “The Chronicles” online: Autopathography and Narrative Associations in an online support group for Chronic Lymphocytic Leukemia

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Often externally invisible, and currently considered incurable, chronic lymphocytic leukemia (CLL) occupies several stages from indolent, through progressive, to terminal in some cases. Variable patterns of disease progression position those with the condition in ongoing negotiation with various points on a conceptual continuum between “wellness” and “illness” with no definitive hope of cure. This ethnography of a chronic disease traces networks of narratives surrounding CLL coalescing in and around the hub of an online support community for people with the disease. Amongst other examples, these include patient stories, medical research papers, online advice for those diagnosed with CLL, medical results and documents. Diagnosed with CLL myself, I have embodied investment and full member status in the research field. Using autopathographic narrative (Couser, 1997), the work will draw on Latour’s object-oriented philosophy to map ways in which these narrative objects are transported and translated around varying experiences of the disease. Autopathography and online ethnography allow for expression of the lifeworlds of those experiencing CLL, and a revealing of how lived experiences of CLL intersect with the texts and technologies that define CLL as a disease through, CLL research, diagnostics, treatment protocols, online support groups and professional support. Particular attention will be given to the impact of differing relations with time experienced by those with chronic disease on their lifeworlds. This paper outlines the project design for my doctoral project on narratives in an online community for those with CLL, and summarizes work in progress. Through this process of early-stage sharing of work to date, the paper considers strategies for innovative and effective presentation of complex assemblages of data incorporating biographical and autobiographical narrative alongside a range of broader narrative, cultural, and technological objects in exploring the experiences of knowing, understanding, and living with chronic, incurable disease.

Keywords: Chronic Lymphocytic Leukemia; auto-ethnography; online support community; actor network theory; narrative; autopathography

Introduction

On a gloomy late afternoon in March, 2011, I left work early to visit my GP and discuss the results of a blood test taken the previous week. Less than an hour later, I sat across from him in the consulting room absorbing the news that I had a chronic form of leukemia. My Doctor told me that Chronic Lymphocytic Leukemia (hereafter CLL) is currently considered incurable, although it is treatable. He told me that those with CLL might die within a relatively short space of time (2-5 years in the worst case scenarios), or they may live twenty years or more with indolent disease.

Despite the overwhelming sensation of shock, several important questions emerged for me that afternoon. They were mainly concerned with my own likely prognosis, the probable impact on my day to day life, what treatment I would require, and whether I would experience pain. My GP was unable to answer most of them. Relatively unfamiliar with the disease, he referred me to a haematology consultant, and advised me to go home and “look it up on the internet”.

In the weeks awaiting my referral, I followed doctor’s orders and looked up everything I could find about CLL on the internet. What I found there was stories. Individual stories of struggle, survival, acceptance, and loss – as varied in their narratives as the lives of those posting them to forums, blogs, and YouTube; practical stories of living with the disease from support agencies and networks; scientific stories of medical research into the condition in online journals; pedagogic stories of diagnosis and management for medical staff; activist stories of awareness and fundraising from campaign groups; stories of everyday and alternative approaches to living with and treating CLL from many perspectives.

The disease began to coalesce for me through the twists, turns, connections and translations of the various narrative objects I encountered. Over the following weeks I learned how to stage the disease according to various combinations of blood work, lymph node enlargement, and organ infiltration using the traditional frameworks established by scientists Rai and Binetⁱ. I learned that I could indeed be dead within five years or less, or that I might survive for twenty-five according to the degree at which my disease would progress. I learned that CLL is regarded as an “old mans’ disease”, most common in an elderly, male population.ⁱⁱ I learned that it is an “orphan disease” (affecting relatively small numbers of individuals),ⁱⁱⁱ that it can be familial, and that evolving cytogenetic knowledge allows for individual approaches to prognosis and treatment. I learned about white blood cells, lymphocytes, apoptosis (programmed cell death), cell mutations and their implications, and the tests and technologies required to ascertain the state of all of these physiological presences or absences. I learned that some people believed that drinking green tea would kill leukemic cells. I learned that many other people were learning (and teaching) about the disease online, all at different stages of progress, and communicating their physical and emotional experiences in online fora, blogs, and user generated video. I learned that there were medical experts sharing their knowledge through research papers, blogs, and videos online. I learned that there were friends and relatives exchanging advice on how to support their loved ones experiencing CLL.

Navigating the Terrain

In those early post-diagnosis days, I was no longer engaged in the familiar internet pastime of trying to second-guess a collection of symptoms prior to seeking a medical consultation. On the contrary, a test tube of blood taken from my arm a week previously translated into figures on a pathology report which, when read against the known norms of blood composition, indicated that I was indeed sick – very sick – so no degree of self diagnostic fear-mongering could trump the evidence on the piece of paper I had folded carefully into my pocket before leaving the GP’s surgery that March afternoon. That was the primary text, the first clue if you like, but now I had to decide where to look next...

I tried starting with medical information. I found medical sites for educating doctors, open-source medical publishing sites for sharing research papers, advice sites from organisations involved with leukemia, or cancer care more generally. Slowly, I started to build up a picture of CLL as it plays out at cellular level, as it infiltrates body systems, as it impacts on psychology, on the ability of those who have it to live their lives, and on life-expectation.

The information was fractured, often out of date (sometimes terrifyingly so) bringing snapshots of an older, less manageable manifestation of the disease into my as yet undiscerning field of vision. Such stories, rendered out of date by recent treatment advances, yet present in the temporal here and now of virtual space began shaping my nascent apprehensions with past prognostics. Similarly, those stories of hopes of a cure for the future borne out of current scientific work on human genomes projected my understanding of and aspirations for the disease into an, as yet, unrealised future.

It was here that I began the ongoing process of suturing together the diverse, temporally unstable fragments I encounter into a fragile fabric of understanding, constantly unpicking and re-stitching as I proceed.

Support Communities as “Hubs”

The discovery of support communities as spaces where all of these disparate narratives came together in the postings, discussions, and interactions of *other people* experiencing CLL was a key moment. That I was not alone in my fear and confusion was a revelation. Of equal importance though was the recognition that these communities acted as *hubs* of collaborative connection between medical, psychological, pragmatic, aesthetic, alternative, existential, employment-related, economically oriented, and social narratives surrounding CLL. Here were rich worlds of narrative inscription, sharing, translating, and hyperlinking bringing ‘CLL on the internet’ into hubs “in here” fixing the spokes to the rims “out there”. Here I could bear witness to, and contribute to a multiplicity of narrative CLLs. I could map translations from one site to another. For example, how does the advanced prognostic testing made possible by work on human genomes and kinomes that I read about in medical research papers translate into narratives of disease progress for community members contributing to a prognosis thread in the support community? How does it translate into my own life expectancy and sense of future?

“In the Blood”: birth of a project

Three worlds of perspective converged for me at this point. The immediate experience of someone recently diagnosed with chronic cancer; the critical perspective of a communications academic; and the knowledge and experience of an ex-nurse. My day to day encounters with the business of being diagnosed as ill were always inflected by my academic and medical knowledge and experience. Like it or not, I was now engaged in an informal auto/ethnography of CLL on a day to day basis. What I experienced and observed made me aware that there is much work to be done on how we “do” chronic illness (particularly cancer) in a digitally connected, scientifically progressive era. The logical step for me was to incorporate my personal research-through-experience into a formal project. “In the Blood” – the doctoral project – was born.

I am indebted to some of the excellent approaches to writing illness already in the public domain (see Frank, 1997; Sontag, 1991; Broyard,1992; Stacey, 1997; Diamond, 1999), which have shaped my sense of the field, and informed my sense that new spaces are opening up in the terrain of experiencing chronic illness that *need* to be written about. The experiences of serious and chronic illnesses are increasingly expressed, performed, and played out within rapidly changing scientific, technological and cultural frames. Two seismic shifts have occurred which between them are changing the way we think about and *do* chronic cancer in the early twenty-first century.

Firstly, the notion of the “e-Patient”^{iv} as the brave new informed, connected, and empowered subject of disease experience begins to displace traditional perspectives of patients as objectified and disempowered objects of a technocratic medical gaze. At present, chronic blood cancer online specifically remains relatively under-researched. In seeking to redress the balance, I follow in the footsteps of those that already begun the work of exploring responses to a range of serious and chronic diseases online from various perspectives (see Sharf, 1997; Høybye,2004; Orgad, 2005; Mahato, 2011; Chou et al., 2011).

Secondly, frontier-breaking medical research, particularly the sequencing of the human genome, opens up new vistas of prognosis and treatment for cancers, hereditary and chronic illnesses, and is exerting a powerful impact on biomedical, cultural, and individual attitudes to disease. My work builds on the observation that this intersection of shifting communication and biomedical technologies and cultures produces important new sites for researching definitions and experiences of serious and chronic disease.

Drawing on a triangulation of Brunor Latour’s Actor Network Theory^v, and auto-ethnographic or autopathographic^{vi} narrative, this project is an ongoing mapping of the narrative objects encountered, engaged with, and created online, and of the networks of connections and translations between them that coalesce to create multiple pictures of a disease that I myself embody. Using an online support community, of which I am a member, as a hub, I will map the range of narrative objects shared and selected for consideration by community members from the many versions of CLL represented online in order to make collaborative sense of a chronic disease that shapes our lives.

My aims are twofold. Firstly, to identify any clear themes emerging from the shared narratives that might provide insight into what it means to live with chronic cancers at the intersection of communication and medical technologies. Secondly, to draw on the flat ontological approach of ANT in mapping the complex assemblage of agents “equally human and non human, semiotic and material, corporeal and technical”^{vii} involved in bringing CLL into being online.

In her ethnography of atherosclerosis, AnneMarie Mol (2002) observes a disease taking shape that is “both material and active.”^{viii} A disease that is made up of activities, experiences, interactions, texts, objects, conversations, drugs, incisions, scars, and stories. Crucially, Mol acknowledges that the stories do not expunge physical reality “patients may interpret bodies, but they also live them”^{ix}. My own ethnography of CLL online asks how the multiple narrative objects circulating and coalescing through dialogue in the support community translate to the lived realities of people with the disease. It uses narrative objects to explore the various ways in which CLL is both done *to* patients, and done *by* them in an embodied, digitally networked, and increasingly genetically decoded world.

Such aims demand a complex assemblage of data, gathered from a diverse range of sites, and in the next section I will attempt to address definitions of ‘site’ in my methodological design for this work.

Defining Site/s

How best can I attempt to define the parameters of this study? What is my site? Where will I locate *myself* as a researcher with full member status of the community I am researching?

These are fundamental questions in relation to any ethnographic project. They are particularly pertinent to this project, which combines autoethnography with a hypertextual mapping approach. ‘Site’ in this case could be variously identified as *myself*; the narratives I encounter; CLL as it is represented through various narrative approaches; the communities that emerge around these narratives; or the technologies that enable their presence on the internet. The latter could accommodate its own *subsets* of computer technologies, biomedical technologies, and technologies of the self. As the work progresses it becomes clear that CLL (both online and off) shape-shifts across and between *all* of these sites, and more. As Christine Hine warns us, “When a technology appears to offer up a clearly defined field site – these sensibilities suggest that one should become suspicious”.^x

A clearly defined research *object* itself is not necessarily any easier to pin down, as John Law and Vicky Singleton’s (2004) ethnography of alcoholic liver disease demonstrates. They found that the disease was enacted in different ways, by different actors, across multiple sites. “This was an object that, as it moved and slipped, also changed its shape”.^{xi} Law is concerned with the relationships between what he describes as the ‘in-here’ and ‘out-there’ versions of the world. For example, disease operating at the site of textbooks enacts the condition as a complex set of “aetiological, environmental, physiological, anatomical, and behavioural relations and effects which match the statements in the text”.^{xii} The writings, drawings graphs, tables and photographs of the textbooks are the ‘in-here’ that represents

one of the ‘out-thereenesses’ of any given disease – its apprehended medical reality. Diseases are enacted at all manner of different sites in addition to their textbook presences, both by people with the disease, and those who care for them. Ontological politics come into play in making decisions about which realities are privileged and inscribed in circulating texts. It is this perspective on the representation, enactment, experience, and politics of disease through different “realities” that led me to identify the MacMillan community as a “hub” within which narrative representations of such realities converge and might usefully be mapped back into broader networks ripe for exploration.

Focusing on MacMillan’s CLL, SLL, and HCL community from my date of diagnosis over a two year period, links will be traced from forum postings out to the narrative objects they address both on the internet and off. These might include lab reports and tests being discussed in the community, research papers, medical education texts, charts, slides, videos, blogs, advice from official support agencies and campaigns, and online images. In order to manage such a diverse range of narrative objects and their connections, findings will be organised under a number of emergent thematic categories. A full outline of themes emerging to date will be detailed in the next section of this paper.

The work will offer a review of the relevant literature and methodological concerns alongside scientific discourse, personal narratives from community members, and texts and images representing the disease (for example: research papers, news features, lab reports, slides of blood samples, screen shots of information videos). The whole will be layered with my own auto/ethnographic narrative as I map the online narrative territory of CLL through my embodied experience. In this way, each chapter will contribute to a rich map of visual and textual narrative connections organised according to emerging themes, and allowing us to build up a dynamic, intertextual understanding of the way chronic diseases are brought into being in contemporary internet cultures. Emerging themes observed to date are detailed below, with a brief outline of the way data will be organised in each section in line with the research aims of mapping flat ontologies of multiple narrative objects.

Emerging Themes

Diagnosis: adaptation-coming to “know” and manage CLL

This section traces the narratives of diagnosis, coming to terms with, and learning about the disease online. The chapter will map medical and professional support narratives translated in the community, alongside lab reports, and other diagnostic texts. Relevant work on illness narratives and their functions informing the work, for example Michael Bury’s 1986 work on biographical disruption,^{xiii} and Robert Faircloth et al’s work on narrative flow^{xiv} will form contextual layers.

Prognosis and its impacts

This section addresses narratives of prognosis, and will map those in relation to the broader biomedical narratives of disease knowledge and management. It pays particular attention to the impact on diagnostics and cultural attitudes to cancer of work on the human genome and kinome. This section will provide a contextual layer drawing in part on the work of Couser (2004) who explores the impact genetic encoding of disease of disease on a sense of self and molecular identity.

Temporal dimensions of chronic illness

This section draws on phenomenological approaches to the experience of chronic illness as a disturbance of Heidegger's "ecstatic temporality", the freedom to improvise our "being towards death".^{xv} Such freedom is disrupted through the temporal boundaries of likely prognosis, the temporal interruptions of treatment regimes, and the temporal incarceration of a chronic dependence on medicine to remain alive. The chapter layers this contextual work with online narratives of temporal disruption in CLL.

Aesthetics – living "well" with disease

Community members bear knowledge of chronicity, of straddling the social perceptions of health and illness, and of accommodating abjection (and perhaps the sublime) into the everyday. This section maps narratives demonstrating how practices of aestheticizing sickness play out within communities concerned with potentially 'incurable' yet chronic or indolent haematological malignancies. These narrative objects express the efforts required to adopt a way of 'wearing' one's involuntary location in the material hinterlands of chronic, progressive, incurable illness. As Alan Radley reminds us, "this is not merely a matter of communication but also the way in which critical moments about illness are established for those concerned."^{xvi}

Relating to others

This section draws on Simmel's concept of the 'stranger' as one whose experience places them outside the boundaries of those around them.^{xvii} This trope of being a stranger in a once familiar landscape post diagnosis is common amongst those writing around illness experiences, is notable in online narratives coalescing in the community, and has been a significant factor in my own experience.

In Conclusion

Diagnosed with a chronic cancer at the crossroads of scientific knowledge and communications technologies, I have described my journey towards and my aims for this

doctoral project, arguing that I am ideally located to map these important new territories as I inhabit and navigate them. I have also argued here that a triangulation of autopathography and the flat ontologies of Bruno Latour's actor network theory provide an effective methodological tool for such a cartographic project. I suggest that ANT foregrounds the connections between the various networks of a chronic disease as they converge in dialogue in an online support community for people with CLL, and I make the case that autopathography allows me to narrate the ethnography of a disease online from the inside - as an embodied and 'knowing' cartographer of the landscape.

This paper provides a brief snapshot of the rationale behind some of my methodological approaches, and has identified the dominant thematic territories emerging in my work to date. Finally, it has outlined a model for organising and presenting complex associations and translations of data in line with my aims to map the narrative network connections involved in bringing CLL into being through an online support community.

Notes

i <http://www.cancer.org/Cancer/Leukemia-ChronicLymphocyticCLL/DetailedGuide/leukemia-chronic-lymphocytic-staging>

ii Brenner H., Gonds, A. and Pulte, D. 2008. 'Trends in long-term survival of patients with chronic lymphocytic leukemia from the 1980s to the early 21st century'. *Blood*. 2008 111: 4916).

iii Aronson, J. K. 2006. 'Rare diseases and orphan drugs'. *British Journal of Clinical Pharmacology*. March; 61(3), 243.

iv Ferguson, Tom, and e-Patients scholars Working Group. 2007. e-patients: How they can help us heal health care. http://e-patients.net/e-Patients_White_Paper.pdf.

v Latour, B. 2007. *Reassembling the social: An Introduction to Actor Network Theory*, (Oxford: Oxford University Press).

vi Couser, G. Thomas. 1997. *Recovering bodies: Illness, disability, and life-writing*. Madison: University of Wisconsin Press.

vii Cypher, Mark and Richardson, Ingrid. 2006. *An actor-network approach to games and virtual environments* (no page numbers)

http://www.mcc.murdoch.edu.au/multimedia/mark/publications/Cypher_Richardson_games1.pdf,

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Mol, *The Body Multiple*, 20.

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Hine, Christine, cited in Markham, Annette and Baym, Nancy (eds.) 2009. *Internet inquiry: Conversations about method* (Thousand Oaks: Sage) 4.

xi

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xii

Law. *After Method*, 71

xiii

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xiv

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xv

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xvi

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xvii

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