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Health Literacy: An Exploration of the Concept in a Life-as-Lived

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Health Literacy:

An Exploration of the Concept in a Life-as-Lived

by

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A THESIS

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Abstract

Health literacy has become a relatively popular notion in the past 15 years in both the policy and professional-practices realms in Canada and abroad. While health literacy has emerged from public health, health education, and health promotion, historically, its increasing presence in discourses surrounding clinical and public health practices has focused on defining, measuring, and operationalising notions of health literacy, rather than attempting to understand what health literacy means to and has to offer the actual individuals implicated in its practice.

In seeking to understand health literacy more deeply, a critical literature review has been undertaken; from this point, in pursuit of a greater appreciation of the overlapping and intersecting notions in the field of health literacy, an auto/ethnographic account of the concept from the perspective of a new mother and a new chronic illness and injury patient has been constructed. What has resulted is a classically composed, but narratively varied, examination of these impressions and experiences.

Ultimately, no common account of health literacy has emerged: rather, what has been found is more closely akin to a ‘family resemblance’, one that presents challenges, and perhaps opportunities, to expand the discussions clinically and publically about this notion that, finally, affects us all.

Acknowledgements

Thank you to all of those who helped care for my babies along the way: my parents, my sister, my husband's family; Andrea, Mischelle, Anna-Maria; Paige & Olivia; and Amanda & Justin.

Thank you to my committee, and most especially Ian, my supervisor, for his everlasting, and seemingly inexhaustible patience.

And most importantly, to my little family:

Me: Well, you did say: "'til death do us part" ...

Paul: Yes. It's just the "in sickness and in health" part that I'm struggling with...

Thank you, and with all my love, Donna

Jack: Mommy, what exactly is wrong with your pancreas?

Me: (long-winded, detailed explanation)

Noah: Mommy, when we get to the next road, can we stop talking about your pancreas?

To my babies: I know that your entire existences have been defined by this work. I know you don't remember mommy before any of this, because both you and this work have come into being at exactly the same time. This book is for you, because of you, and belongs to you.

I love you with every fibre of my being.

Mommy

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Epigraph

'The truth,' Dumbledore sighed. 'It is a beautiful and terrible thing, and should therefore be treated with great caution. However, I shall answer your questions unless I have a very good reason not to, in which case I beg you'll forgive me. I shall not, of course, lie.'

(Rowling, 1997, p. 216)

Act One: Getting Critical

Critical illness offers the experience of being taken to the threshold of life, from which you can see where your life could end. From that vantage point you are both forced and allowed to think in new ways about the value of your life. Alive but detached from everyday living, you can finally stop to consider why you live as you have and what future you would like, if any future is possible. Illness takes away parts of your life, but in doing so it gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years.

(Frank, 1991, p. 1)

Born into a world she does not create and more inexorably into a future she cannot entirely anticipate, such a being above all else is mortal: circumscribed, vulnerable and limited.

(Kerdeman, 1998, p. 257)

If the text does not have serious intentions, the seduction does not tempt us.

(Nielsen, 1995, p. 11)

scene i: A Teaser

At the very beginning of my academic program (July 2006), while taking my Qualitative Methods course, I came across a reading in Denzin & Lincoln's much-cited *Collecting and Interpreting Qualitative Materials* (2003) entitled "The Qualitative Researcher as Bricoleur and Quilt Maker" (p. 5-9). In it, they stated (after Becker, 1998): "The qualitative researcher as *bricoleur* [ital. in orig.]...uses the aesthetic and material tools of his or her craft, deploying whatever strategies, methods, or empirical materials are at hand" (p. 6). Understandably, what is used, how it is used, and when it is used depends almost entirely upon what is being studied, and what is imagined to be required at the various moments of the research. It is flexible, responsive: it relies upon the individual's capacity to critically reflect upon *process*, not content or intended outcome.

While Denzin & Lincoln did introduce the five dimensions of bricolage – methodological, theoretical, interpretive, political, and narrative – in their work, it was Kincheloe's (2005) work that proved most useful to me in beginning to truly appreciate the complexity, and utility, of the approach. Fleshing out the five dimensions, he laid a veritable smorgasbord in front of me. As someone at the beginning of an academic program, to be given such *carte blanche* was thrilling (not the more apt 'daunting' I should have recognised it as). I did not have a clear idea of what I wanted to study as yet, but I knew that when I *did* arrive upon it, I would want to adopt a bricoleur's panache. I wanted to explore up and down, backwards, forwards, under, and around. I wanted to find hidden connections, really chew upon the texture of the topic, and venture beyond the traditional and 'authorised' texts and tools of the discipline or academic domain, whatever it might end up being.

The other interpretive insight I took from those early days was Richardson's notion of *crystallization* (2003, p. 517). She advocated taking up the object of study from multiple stances, akin to turning a crystal in your hand to see how it reflects and refracts: in doing so, you will necessarily see different things. Objects of study, like crystals, will never be exhausted of their variability – the perspective you take, the lighting you use, the background, all of these influence what you might see. This was provocative to me: the idea that there wasn't a concretely defined 'right' way to look at something freed me from the anxiety that I felt when confronted with choosing 'just one approach'.

Taking these two conceptualisations – the bricolage and the crystal – I embarked upon my academic journey. It would be difficult to underestimate the influence of these concepts upon how I approached what was to come: by embracing these two ideas, I opened myself to both the theoretical and practical insights that broad contributions make one's research (in other words, not staying within the strictly delineated confines of a discipline's authorised discourse), and to considering the issue(s) from diverse perspectives, within one's own self.

Now I just needed a topic.

scene ii: Reflection

It's a Saturday afternoon in April and my sunlit day is gone: Outside, the spring flurries swirl and gust around my little cottage in the mountains, coating everything with an ebb and flow of white. I'm not really surprised: a lifetime in this place has taught me about meteorological caprice. This is the first time that I can remember, though, making the observations I have today. As I sit contemplating my little world, I notice how the snow has made my horizon shrink – I can only see the two cottages down from me, and a little

bit further on beyond that to the campground, but nothing further. I know that before me rise some of the most beautiful mountains in the world, but I see none of them. The snowy haze that has descended has obscured these ancient rocks, and truly, if I were encountering this place for the first time, I would have no idea what my world really looked like – I would only have these bits of cabin, that bit of campground, as my immediate, sodden domain.

I am struck at how apt this observation is as a metaphor for what I have encountered these past seven years. When I began down this road, I could only see the cottages and the campground – my own little realm – and, while confident I could tackle anything that came my way, I hadn't any idea that mountains surrounded me. Now, these seven years later, I know that there are mountains around me, even when I can't see them – they affect my climate, my viewpoint, the amount of daylight I enjoy, limiting me and protecting me whilst offering the enchantment of unseen vistas and unknown passages.

That is what this story is about: the discovery of mountains. And with these discoveries, the host of emotions that come with them – exhilaration, fear, curiosity, intimidation, acceptance, humility, and wonder.

Seven years ago I picked up the term 'health literacy', intent on understanding it as a curriculum developer and educator. I had imagined, at the time, that this term denoted something that individuals could possess (as in you are or aren't 'literate'), and if they could possess it, then perhaps they could be taught it. My idea was to take the concept, and look at developing ways that educational interventions might be designed for various populations, at various stages in their life. I naïvely believed that, if people could be taught

to be ‘health literate’, then they could be more engaged and more responsible in their own lives, and in the lives of those for whom they care.

I say ‘naïvely’, because the term ‘health literacy’, and all that it can and does mean, and how it is situationally-determined and politically-fraught, was nothing more than a neutral, maybe even benevolent, notion to me. It remained unchallenged in my mind, existing in an unsophisticated sphere where everyone could *learn* to be health literate, and therefore enjoy the largesse of our system, just like I did.

I had recently been through the birth of our first child, as well as the diagnosis of my own life-threatening genetic condition. I was still coasting on pride and a sense of superiority, knowing that I had been well prepared (in all respects) for the birth, and that I had managed the clinical realities of my genetic condition with an uncommon aplomb, afforded by my past experiences with the health-care system, my educational level, and my inherent interest in health and medical matters. If I make myself sound conceited and self-important, I assure you - I was.

Mountains were around me, to be sure: it is through the benefit of hindsight that I can see them outlined in my mental landscape. At the time, I didn’t realise anything might be amiss. It is not as though I was oblivious: I was certainly sceptical of many things, including medical experiences, within a sort of postmodern bourgeois perspective. It was just that I felt confident that I could discern the proper course of action in a situation – I could find the right information, I could advocate for myself, I could make do. Problematising any aspect of my experience was far from my mind.

Something changed, however. I didn’t undergo any of the transformative experiences that many write about, I didn’t wake up one day and ‘see the light’ – my

change was spurred on by something far more subtle and creeping. Education changed me. I've said that I was educated *before* I reached this point in my life, and that's true. I'd completed Masters-level education (in Education, no less). I had a host of other credentials and experiences. As far as 'achievement' was concerned, I was a success. I *knew* things. Staunchly embedded in my culture, I could see quite clearly what was in front of me. But not what might be beyond me, or even beside me. The thought of looking at horizons, and then *challenging* them – well, that hadn't even begun to occur to me.

So, how did 'education' change me? It's hard to put my finger on it precisely, but I do suspect the process began when I started my doctoral program. Not to be deterred by new motherhood or chronic illness, finishing post-secondary schooling seemed like a good way to spend my 'free' time, now that I would be a stay-at-home mother. I chose to specialise in Curriculum, Teaching and Learning, largely because that defined the majority of work I'd done to that point; that, and I had this notion that curriculum, teaching, and learning undergirded everything in our world, and nothing else was as universally applicable. What I was going to *do* with this additional education remained to be seen.

As I attempted to balance the new expectations (and massive amounts of reading) that my brilliant plan had initiated, I was unaware of what was happening. It was a very, very slow process in the beginning. I had done work utilising Augusto Boal and his Theatre of the Oppressed in my undergraduate drama degree, having been part of a study funded by the Chinook Health Region and Health Canada (Regional Centre for Health Promotion & Community Studies, n.d.). We worked with Aboriginal and rural populations to create new ways of engaging in and understanding health and health care interactions, but it hadn't occurred to me that this research might be relevant to *me*. I still didn't connect

the dots when I was required to read critical theory or feminist theory or curriculum theory. I was blithely planning my health literacy curricular interventions, as I mentioned earlier, without a thought to what else might be made of my work.

And still I kept reading. Critical theory led to feminist theory, and from there I encountered maternal theory. At the same time, I was also reading all I could on Health Literacy. Something did not seem quite right. I began to suspect that there was a far more complicated way to understand Health Literacy, my intentions, and my perspectives. I kept following trails, back in to the past, over into other theoretical realms, and through myriad media sources. I read about literacy, medical sociology and history, ethnography and auto/ethnography, women's epistemology, metaphor, illness identity, maternal thinking, narrative, media theory, pedagogy, rhetoric, discourse analysis, frame analysis, Gadamer, Foucault, Ricoeur, Pinar, Aoki, Slattery, McLaren, and the more I read, the more dark pathways I found. Still, my avowed focus was on curriculum – as in *developing* curriculum, to be used by other, more unfortunate and needy individuals. Like doctors.

It is true: by this point, I had determined, if only in my mind, that the majority of health literacy challenges could be solved by educational interventions aimed at those most senior in the health care world – the doctors and the specialists. It seemed inherently more sensible to train up several thousand medical specialists in understanding communication and cultural differences as they applied to health and wellness than it did to try and retroactively educate millions, perhaps even *billions*, of potential patients. Of course, the school systems could be leveraged to teach patients of the future, but it was the patients of *now* that posed the greatest challenges, in terms of time and cost (because, I had learnt,

those were the determining factors that leant ‘health literacy’ any credence in many circles).

Here I realised I differed substantively from the bulk of the health literacy literature (which I will go into in a bit) when it came to the balance sheet of health literacy interventions: while there was a body of work that recommended strategies for doctors learning to be better communicators, the focus was well and truly upon patients becoming better *patients* and individuals becoming better (read: more responsible) *citizens*. And that’s where I really started to feel myself slip sideways. Perhaps it was because my experiences as a *patient* and as a *parent* didn’t resonate with what I was reading. Perhaps it was because I had begun to read Freire, Pinar, McLaren and Macedo. Whatever the reason, it all seemed too *simple* and too *colonised*: there was a recommended way of thinking and behaving, with rewards for those that complied, and denial of rewards (which is not the same as punishment, necessarily) for those who did not. I found myself using words, like ‘colonised’, in ways that I had never even conceived of them before, and the world started looking very different from that which had been in front of me a mere year ago. I could start to see the outlines of my metaphorical mountains.

Lest you think that I was one of those groupies that jumps all over radical ideas in university, disassociating from all that came before, renouncing animal products and popular music, here I stop you: While I wasn’t quite the opposite, a supporter and purveyor of the culturally dominant, neither was I the type to cast my lot with the revolutionaries. I had even made fun of a few contemporary critical theorists: their flamboyant and inflammatory rhetoric was laughable given their position in the elite (as tenured professors and published authors). They seemed to be trying to co-opt the minority

experience of others for their own professional purposes, rather than for the solidarity they purported.

Ah, but the joke was on me: Despite my shallow and unsophisticated take on ideas and theories like those encompassed in critical theory, they were working on my psyche in ways I had not anticipated. About the time I used the term ‘underbelly’ in a presentation on curriculum theory, and it was praised (I think this might have been because I even had an inkling there was such a notion as ‘underbelly’), I realised how differently I had begun to see the world around me. Of course my ideas about ‘underbellies’ and ‘hidden curriculums’ were thoroughly unoriginal, still I felt that something was new to me.

It all might have amounted to a brief existential fling, had it not been for the personal challenges that I was encountering alongside these new thoughts and ideas. While attempting to read, write and think about health literacy and these new theories and ideas that my required (and not-so-required) reading introduced into my mental framework, I was encountering a whole host of health challenges that contextualised these new bits of thinking. With each new experience, whether as a mother or as a patient, I found my perspective edging towards the margins. The margins of what? you ask: the margins of acceptable thinking, perhaps. Or maybe I mean something more akin to the margins of *thinkable* thought, at least in terms of what was (and more or less *is*) extant in the world of words related to health literacy.

This is an important point, this last: because it drives to the heart of my work. With each of us, we experience a world, true – but my world, and your world, and somebody across the street’s world, or my sons’ worlds, they are different. Sometimes substantively, sometimes subtly, but always different. And as we are inculcated into our respective

worlds, we learn the *words* to talk about these worlds. Much of the time, the world we experience and the words we use are more or less synchronous. Or perhaps it is more accurate to say that they *seem* to be in tune because they are used or experienced without thought. Discordance manifests when the words being used or taught differ from the *world* being lived in. These are not new thoughts, as anyone who has had the opportunity to read Freire's work will attest.

I am not trying to get into a deep philosophical discussion about how words come to mean what they do, or the role of metaphor in the construction of thought, or perception, or any of those aspects of scholarly thought. There are others who do better and more with them than I could ever hope to. What I am trying to touch upon is how we manage when what we *experience* and what we're *taught* (formally and informally) do not match. Where do we go from there? How do we resolve the cognitive dissonance that results?

These questions came to me only in hindsight. Remember, I was officially studying *health literacy*. But as I read and thought about all that was being said about health literacy, as well as the theoretical reading that was ostensibly separate from my study-proper, life was happening, and no better fruit for study can be imagined. Not wanting to give away the plotline, I will only tell you some of the new words I have learned over seven years as a layperson (and *not* because I felt like reading a little more on the side): hypertriglyceridemia, congenital torticollis, ringworm, microdissectomy, fibrinogen, enervation, denervation, paediatric cardiology, paediatric haematology, glioblastoma, cystocele, rectocele, enterocele, plagiocephaly, hypogammaglobulinemia, adjuvant, and flocculent. And this is the (very) *short* list of terminological candidates.

Sufficed to say, I have been *living* the process of health literacy during this study, in a heightened way that is not often found, and certainly not written about in the academic register. This is what this study will bring to the ongoing discussions around health literacy: the unique perspective and voice both *theory* and *practice*, at the grassroots experiential level, can provide, as a mother, a patient, and a researcher.

Act Two: The Contextual

Theory, for me, has always been an act of creation rather than the presentation of a preformed set of concepts in some systematic manner. It has been an attempt to disclose something not yet clearly perceived or conceived, rather than a presentation of a picture of some phenomena.

(MacDonald, 1982, p. 58)

Performance thrills me, theory does not. I would surely lose myself without performance, but I cannot live well without theory.

(Madison, 1999, p. 109)

These “textual forms [are] the effects of the fragments and wreckage of experience.”

(Spry, 2006, p. 341)

Auto/Ethnography of a Prairie Woman...a Beginning

Yet such memories don't necessarily have to be in the first person to shape our lives. (Pollan, 2013, p. 84)

It is undeniable that our understandings of ourselves and of the world are directly attributable to our upbringing. Innumerable things contribute to this, including our language, our culture, our geography, our education, our spirituality, our gender, our relative access to resources, and our physical experiences. It is impossible to fully catalogue and understand these things as they apply to us, let alone to others. That doesn't make the pursuit of such knowledge a fruitless enterprise; however, it *does* mean that everything we 'know', we know contingently and provisionally. It is the proverbial 'taken with a grain of salt'.

With this in mind, I embark on a partial reflection upon my maternal (in the sense of those that mothered) forebears – or, at least, the ones I have known in my life. What I mostly have at my disposal are stories and impressions –whether they are 'truthful' or not is irrelevant – they are what I have and thus they are what has shaped me. These stories contribute to my own story, and the culmination is, effectively, a critical part of my psychic 'fingerprint'.

It's hard indeed to look back over the lives of my female antecedents without being struck by the differences in how their identities were defined and their existences lived out as compared to mine. How they lived, how they cared, how they coped, what health meant, and who was responsible for health – so very much has changed in less than 100 years.

I can catch glimpses of my maternal grandmother crossing the Atlantic with her family, at ten years of age, to start again in a new country, with a new language, a new culture. The chance for something better than the rural peasant life left behind north of Budapest. To find herself in a cloistered Hungarian Canadian community, where her mother never learned a word of English, never setting a foot in a Canadian school because she was needed at home to care for the never-ending string of little ones, her existence was defined by the quotidian details of health and care of others. Drawing from the well in the backyard, picking the vegetables in the teeming vegetable plot, hoping to marry ‘up’ and have children who could do better, more.

Or my paternal great-grandmother, crossing the Atlantic as well, this time at 21 years of age, with her entire family, all on the promise of their own land, something not available to them in Scotland. She, marrying a farmer, and giving birth to endless children, some surviving, some not – having my grandmother (the oldest girl) stay home by Grade Eight just so that there was another set of hands to help with the babies. Her older brother went to school: boys needed education, after all.

Or my maternal grandmother, caught in the endless cycle of working-class poverty, fuelled by no education, no opportunity, and addictions. Giving birth to my mother, the third (surviving) of five, at twenty-two, constantly moving from one tumbledown house to another, never more than a paycheque away from the repo man. Or my mother, vowing to do better, getting babysitting jobs to pay for her own dental care, her own hygienic products, while still essentially a child, sights set on a way out.

Or my paternal grandmother, caught in the war years, when farmhands weren’t drafted because their work was vital for the war effort abroad, but women filled so many

other freshly available positions. Marrying a farm mechanic, still poor, scrimping and saving and sacrificing so that a sick child (my father) could get medical help (and that child's father – my grandfather – would go without lunches for a month to make up the shortfall). I don't know what my grandmother went without.

These are but the tiniest of glimpses into those moments that made these women, and ultimately, made me: they are important, and such stories risk being lost amidst the tide of 'knowledge' that constructs our current everyday. Any attempt to understand 'me' starts with 'them'.

Slowly, slowly, my predecessors have inched forward, most on the Canadian prairies now for two or more generations, through all the years when public health made its greatest gains, and benefited legions of immigrants and citizens. Not a single person from the many that have led to my existence has had political inclinations or reformatory ideas that have survived in family lore. Undeniably they have all profited from the monumental changes in public health policy that has allowed my life (statistically-speaking), but I doubt very much that they gave a lot of thought to those facts. My great-grandmothers were glad to have water piped – calling it 'Public Health' or 'Public Works' was irrelevant. My grandmothers taking their children for vaccines? Well, they didn't call it 'health promotion' – they called it 'protecting their children'. My mother had no idea that all the little immunisation cards and yearly check-ups (body, eyes, teeth) and '4 Food Groups' were the product of "health education". Life is complicated enough without analysing the details of governmental policy or professional practice.

So, sitting here in 2013, I must remind myself: life has *not* always looked like this. How my great-grandmothers, grandmothers, and mother define 'health' (and almost

everything else) has changed with every generation (and even within the generation), as culture, geography, language and technology swirled around. And what I believe about health, about health care, and health agency, about whose role is whose, and about what I can or should or might expect from that thing we call ‘health care’, well, all these things are constantly changing, too. What is defined as a disease (or how I define my body’s ‘healthiness’) can switch in an instant. What is understood as ‘best practice’ for child health is unmerciful to mothers, more so nowadays with quicksilver technology – today what you do for your child’s wellbeing is the very thing that may make them sick tomorrow. And it is increasingly the case that those that have *less*, whether it’s education, income, access to technology, youth, confidence, social standing, and so forth, are falling behind in this race to ‘stay educated’ for health.

I often think of my grandmother. Several years ago now, I received a call from my mother:

“Grandma’s in the hospital.”

“Why?”

“She’s on suicide watch.”

“WHAT?!?”

My mother starts snickering. “They think she’s suicidal because she washed down her medications with whiskey.”

I start laughing, too. “But she’s always done that! Why is it a problem now?”

“Because she has a new med, and I guess it reacted badly. But she has, like, 14 pills to take at once.”

I reflect: “I’d use whiskey, too.”

Of course my mother and I know that it isn't particularly wise to combine alcohol and medications. We've told grandma this, but she doesn't care: she's always had her evening glass of whiskey, and she feels that it's an infringement upon her person to be told otherwise. There is also the (perhaps more important) concern about a life defined by a pile of pills every evening, a doctor that continually prescribes them without thought to the potential consequences, and a pharmacy that continually fills these prescriptions without comment or concern.

But here in 2013, in Canada, while we still live with (and enjoy) the legacies of public health, health promotion, and health education, we are faced with another incarnation – health literacy. And the difference between my maternal ancestors and myself is simply that I know that it is there, operating as a philosophy that is driving policy and communication, and I am raising my own children in this brave new world. It behoves me to care, because this new way of conceptualising *what* health is, and *who* is responsible for making choices, pushes and pulls at me every day as I try and make decisions about the health and wellness care that I provide for my children, and for myself. There is an undercurrent that holds (it seems) that we all should be 'health literate' to minimise confusion, but what are we asking of each other and ourselves in doing so? My grandmother, above: Is she health illiterate? What portion of the responsibility (or blame) is systemic versus individual? If she knows, but doesn't care or take action, is she health literate, or not? These are important questions, ones that I will continue to ask during the course of this thesis.

scene i: Health Literacy,

Literature reviews can be a messy business. Certainly there are many fields in which there is a corpus of work that is clearly prerequisite to working in the discipline, and ideally, as you hone in on your specialisation, you come into increasingly narrow waters. What you gain in depth you sacrifice in breadth, and this is entirely understandable – and necessary. But what happens when there *isn't* such a plainly delineated canon? In January 2006, this was more or less the case for any search on 'health literacy'.

My preliminary (and very loose) search pulled up two papers: "Health Literacy: Report of the Council on Scientific Affairs" (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association, 1999) and "Health and Literacy Perspectives in 2002" (Shohet, 2002). There were a few other 'hits' at the time, including Kickbusch, Nutbeam, and Rootman, and to those individuals I will eventually return. However, in the absence of any formative notions otherwise, I chose the first two – and the choices turned out to be more useful than I could have imagined.

The Council's report, as the first (and only) position paper issued by the American Medical Association [AMA] on the concept of health literacy, set the groundwork for all future discussions of the topic within the American clinical constituency. The report itself actually provided *two* definitions of health literacy, both still in use today. First: "An individual's functional health literacy – the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient" (p. 552). In this same document, an alternate definition is also provided: "Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.

Patients with adequate health literacy can read, understand, and act on health care information” (p. 553). Both definitions circle around the same issues: patients’ ability to adequately function in the prevalent health and medical environment, with that adequacy being contingent upon *correct action* defined by an external source. In the beginning, I had no issue with these definitions.

The AMA article did a thorough job of identifying a host of concerns that still preoccupy theorists and practitioners today, including culturally and linguistically appropriate communication skills and materials, plain language informational and educational materials, a concern for socioeconomic factors, the connection between education level and health status, physician assessment of patient health literacy, physician communication skills, the societal costs of poor health literacy, the legal ramifications of treating patients with poor health literacy, empowerment, and medical establishment ownership of the health literacy ‘problem’. Such a broad introduction to the scope and implications of health literacy as an emerging field of inquiry was promising, if daunting. It was evident, even in those early days, that the medical field positioned itself (understandably, at least to a point) in the top-down orientation of a discipline which had the power to influence, if not outright control, this notion of ‘health literacy’, both as experienced, and as understood, by the patient.

At only one point does the possibility of a bottom-up approach get broached:

...there is no constituency for health literacy. Without a group of consumers to call attention to their “problem,” a group of health care professionals whose livelihood depends on dealing with the problem, or a government agency charged to address

the issue with appropriate resources, health literacy will remain tangential to the US health care system. (p. 556)

Even this is rather roundabout way of approaching the idea. In order for a ‘group of consumers to call attention to their problem’ requires, at minimum, a) consumers to recognise that there *is* a problem, and b) such recognition to consist of consumers identifying that problem as a problem with their *health literacy*. Both aspects presuppose a health literacy that is based on a medical model that relies on *compliance*: neither presents a definition that problematises the relationship between medical authority and patient action (never mind any of the additional factors that influence or mediate a patient’s ability or willingness to participate). The goal became the creation of a health literacy constituency – practitioners and policy-makers who believed in the necessity of placing health literacy at the forefront of discussions and actions, alongside a public that was to be increasingly made aware of their due diligence in respect to proper health action (“health literacy”), even if they had no clue it was being called “health literacy” by those pulling the educational and social marketing strings.

The second article, Shohet’s, takes a more diverse perspective on health literacy. Shohet was (and still is) an adult literacy educator: she founded, and continues to serve as the director of the Centre for Literacy in Quebec, Canada (www.centreforliteracy.qc.ca). The article, “Health and Literacy: Perspectives in 2002”, was a commissioned paper for an Australian consortium holding an online discussion forum on the connection between literacy and health. This interest from the public health community (and Shohet, in her continuing work) continues along the lines that brought Ottawa Charter into being (World Health Organization, First International Conference on Health Promotion, 1986) almost

twenty years prior. While the Charter does not use the term *health literacy*, it does contain the kernel of an *idea* that many (though not all) have argued is substantively different than *health promotion*. It is this seed that Shohet picked up for this paper, and for which there was already a groundswell of interest in Australia. While Shohet talked very briefly about the range of understandings of ‘literacy’ (starting with reading and writing), the article took an empowerment/Freirean-orientated (Freire, 1970/2008; Freire & Macedo, 1987; Macedo, 2006) perspective on literacy. Shohet drew definitions and examples from public health organisations and community-based information sources, and the article itself served as something of a crash-course in the emergent ‘health literacy’ field, circa 2002.

The most salient discussion, beyond the diversity of definitions she presented, revolved around Nutbeam’s levels of health literacy (2000). Shohet alerted me to the possibility that there was more than one way to conceptualise health literacy – I had easily and unquestioningly adopted the functional health literacy standpoint of the medical definition of health, though not, of course, recognising it as such. Functional, interactive, and critical health literacy levels, imagined in a continuum, appealed to my experience as an educator – enchanted as I was by notions of evolution and empowerment. It was in this realisation that a ‘spectrum of health literacies’ might exist that I conceived of the notion that perhaps the medical community (clinical) and the policy/adult education community (public) could be talking about the same thing (health literacy), but *on different levels or from different perspectives*. This was, of course, only a nascent thought, and it wouldn’t be until well into the future that it would grow into anything discernible. Introduced as I was to the concept of health literacy through these two articles, the stage was set for me to explore a more proper literature “review”.

scene ii: Health Literacy, the Birth

It would a bold lie to say that this literature review process has been either straightforward or easy (like I said earlier, ‘messy’ is more apt). It has felt more like tracing the various particles’ trajectory after the Big Bang: following one meant that you rapidly lost track of another, and even when you tried to create a map of what was happening, how each speck’s movement through space and time influenced all the others’, you were hopelessly disoriented before you even began.

For instance, after my success with the AMA’s report, and Shohet’s discussion paper, I merrily undertook the standard literature search on MedLine and PubMed for the term, and had little luck with titles containing ‘health literacy’: However, when I switched the search to keywords ‘health + literacy’, I got a few more hits, and even a few more with a full text search. I read those articles and consulted their references for further resources. I quickly found myself in all kinds of databases and journals I’d never heard of, across all kinds of disciplines. Soon I realised that, despite the fact that certain words or concepts were used, they were, in fact, being used rather loosely, with little critical thought. It became readily apparent within a few months that I would have rather left these ideas untouched – I could see why people were using ‘health literacy’ in an unreflective manner – unpacking ‘health’ alone was a lifetime’s work. Such an abstract moral and ethical minefield does not lend itself to easy analysis. Further, ‘literacy’ is a complicated notion that has been evolving in many sectors of society in recent decades, lending an air of confusion to health ‘literacy’. And then there’s health literacy’s ancestry – public works, public health, health promotion and health education – these relationships, at various times,

appear linear, concentric, web-like and multi-layered, imparting all sorts of challenges to interpretation.

As a result, I have had to spend a considerable amount of time grappling with these notions and histories: while I do not purport to have anything resembling consensus from any source whatsoever, what I *do* have now is a much clearer sense of how thoroughly *unclear* these notions can be and are, for the most part, and what the implications might be for any deep and critical understanding of ‘health literacy’. It is to these three areas we now turn briefly, in an attempt to provide a bit of forethought before returning to health literacy-proper.

Interlude One: How Do We Understand ‘Health’?

Before looking at how ‘public’, ‘promotion’ and ‘education’ fit together, a common, or at least working, understanding of the word ‘health’ is required. Like holding a crystal, the more we tilt and turn the word, the more we see, much like asking any one person to give his or her own definition ‘health’ is likely to result in a wide range of responses.

If I were to ask you right now to define ‘health’, what would you say? Chances are you’d mention how you feel, how you function, whether you are able to do what you want to, whether you are able to do what you need to. The word ‘balance’ might pop up, as might things like ‘physical’, ‘mental’, ‘emotional’, and ‘spiritual’. You might say that ‘health’ is the absence of illness, or disease, or simply the absence of ‘something wrong’.

You might tell me you don’t think about health. You might tell me that the best way to deal with ‘something wrong’ is to buck up. It will pass, or you will die – one of the two. You might also tell me that there’s a prescription for that, or an ‘alternative’ or

‘holistic’ practitioner that would help with that, or an online site, or a support group (or nowadays, more likely a blog or a chatroom).

Depending upon where you are from (and when) your definition of ‘health’ might include certain dietary observations or physical practices or spiritual adherences. Health might simply mean you are still able to care for those around you. It might mean you’re able to work – whether it’s in a field or at a desk.

It’s also possible that you take offense to even being asked. Health might be an immensely private matter. Or you might take my question as an opportunity to chronicle all the myriad ways in which you are (or aren’t) healthy. Health might also be the province of the individual, just the same as it could be the concern of the state. It might arguably fall into the jurisdiction of the gods. It is possible to think of health as a *privilege* and it is equally feasible to think of it as a *right*.

The World Health Organization stated: “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 2003). This definition, adopted by the International Health Conference, held in New York City, June 19 – July 22, 1946, was signed by 61 member states on the final day of the Conference. It entered into force April 7, 1948, and has not been changed since that moment (p. 100). Such a positive conceptualisation moves it away from a purely disease-driven model. Skipping forward forty years, the Ottawa Charter built upon this ‘social model’ (Yuill, Crinson, & Duncan, 2010) definition and understanding by adding: “health is a positive concept emphasizing social and personal resources, as well as physical capacities” (p. 1). The crux of the charter was its

commitment (by signing members) to make substantive gains for individuals and communities in terms of overall ‘health’.

However, as Blaxter (2004) pointed out, the contemporary biomedical model, which was (and is) largely based upon the disease model – and which I will call the clinical model going forward – viewed the situation differently: “social and psychological causes of ill health – stress, unhappiness, life events – are admitted as agents of disease, or contributing factors, but they are not themselves defined as ill health” (p. 15). The clinical conception of health care has not typically focused on the psychosocial factors, beyond screening for abuse, depression, and so forth. However, there is danger in decontextualising both the illness and the person for the sake of “value-free scientific principles” (Radley, 1993, p. 6) – in the case of depression, for instance, there is little a doctor can or does do beyond prescribing medication, perhaps counselling, and the suggestion of ‘getting help from your support system’. Depression is a recognisable set of symptoms that is (or at least, can be) treated by the drug-of-the-day: Clinical medicine, however useful, has little to say about the kind of health/depression that arises from being depressed about being sick, staying home with children all day every day, or knowing that your living conditions are dire.

What we mean when we use the word ‘health’ will, of course, have a direct impact upon what we mean when we say ‘health literacy’. And that same meaning will set up expectations – expectations of our selves, and of others. It is hard to imagine an understanding of ‘health’ independent of the cultural context in which we find ourselves – in other words, we come to think of health based upon what we are told is health – and by telling, I not only refer to the explicit, but the implicit as well. We might think we’re

operating independently in our notions (and there is always some degree of individual variability), but the truth is that we are conditioned – we are, effectively, educated. Depending upon the definition or understanding of health we consciously or unconsciously subscribe to, we then judge our status accordingly. What happens, then, when the definitions or understandings set up are unattainable? Or don't make the culturally dominant definition?

By the WHO's definition of health, "complete physical, mental, and social well-being", I am not healthy. Neither are my sons, my parents, my siblings, my husband, my friends, nor anyone else around me in my avowedly western middle-class environment, for none of us possesses the illusive "complete". It is doubtful that any of us will *ever* be healthy by this ephemeral definition. This, to me, is intriguing. Who, then, *is* healthy? What are we chasing?

Blaxter (2004) pointed out that much of our understanding of 'health' is attached to our concept of normal:

...normal can be descriptive or proscriptive, and if it is proscriptive it has to depend on the state of knowledge or accepted current theory...there is a great range of normal variability, and only that which falls outside it need be considered as ill health. The range has still to be defined, perhaps arbitrarily. (p. 5)

The 'range' that is defined is cultural: so, too, is what is defined (though biomedicine certainly strives to rectify this situation). Radley observed, for instance, "the lay perspective shows that how people think about health and illness varies with their position in society, so that this discourse is itself informed by their interests in other spheres of life" (1993, p. 2). Whether that culture is defined linguistically, socioeconomically,

geographically, gender-wise, technologically, and so forth, the fact remains that notions of 'health' remain contingent, and as such, problematic for purposes of a definition.

A contemporary example is found in debates surrounding menopause and HRT (hormone replacement therapy) – the medicalisation of a natural female stage through diagnosis and pharmaceutical intervention (Brizendine, 2006; Mahowald, 2006; Moynihan & Cassels, 2005). Advocates claim that this is a sign of health and wellness 'progress' – the alleviation of a 'condition' that has historically incapacitated some women through a pharmaceutically-developed and -delivered intervention. Detractors argue that it is merely an encroachment by the medical establishment (in cahoots with the pharmaceutical industry) into the otherwise normal lives of menopausal women, one that redefines them as 'ill' and in need of the medical establishment. Is a woman going through menopause 'ill'? Is she 'less-than-well'? Or is she healthy? Who decides this? And what are the implications of such decisions? The expansionist tendencies of biomedicine make it difficult to hold one's ground in the argument of a 'normal' range of human experience, because what is considered 'ill' seems to continue to expand, not contract. If one waits long enough, perhaps ranges will become a thing of the past.

As such, there is an argument to be made for health hubris. Illich (1976/2002) noted

The Greeks saw gods in the forces of nature. For them, nemesis represented divine vengeance visited upon mortals who infringe on those prerogatives the gods enviously guard for themselves. Nemesis was the inevitable punishment for attempts to be a hero rather than a human being. Like most abstract Greek nouns, Nemesis took the shape of a divinity. She represented nature's response to *hubris*:

to the individual's presumption in seeking to acquire the attributes of a god. Our contemporary hygienic hubris has led to the new syndrome of medical nemesis. (pp. 34-35)

In this vision, the ever-expanding biomedical notions of health begin to come close to this idea of over-reaching – by continually reinventing health as something that falls increasingly under the purview of human control in an widening circle of factors, we pursue something more akin to an *ideal* than what might be argued as *normal* (Stark, 2006). Quickly, though, we find ourselves back into the “what is normal/who gets to define normal?” debate, with little hope of resolution. All of this, yes, is reported from the stance of a Western biomedical upbringing and perspective, whatever the evolutionary point these concepts might be currently at.

The fact of the matter, of course, is that the creature we know as human has been dealing with many (if not most) of these diseases, conditions, ranges and so forth, for time out of mind. Given the current global population, it is easy to argue that the human body has been very successful in this regard. McKeown (1979) contended that Western biomedicine is *not* the primary factor behind this triumph: rather, it was those elements mostly closely attributed to public works and public health (clean water, clean food, immunisations, improved sanitary conditions) that ought to be thanked. Even if we assume that 80% of human health-related situations can be improved or resolved through these fairly simple steps, there still remain 20% that are outliers. This is the 20% that biomedicine most clearly impacts.

And this 20% appears to matter a very great deal to the majority of the world, if we are to take the spread of Western biomedicine around the globe as proof. Of course, there

are certainly arguments to be made for capitalism and colonialism's influence upon this increase, and exposure is certainly a contributing factor to the rapid dissemination of the knowledge, technology, skills, and pharmaceuticals. Davis (2002) suggested that culture could be contagious; Dutta & de Souza (2008) claimed that

The very campaigns that were produced to generate development have contributed toward the disenfranchisement of cultural members by pushing an alien set of values, by undermining local values, and by seeking to erase local knowledge with the goals of replacing such knowledge with Western knowledge that qualified as universal scientific knowledge. In doing so, health campaigns pushed a seemingly secular universal framework, but in reality this framework was embedded in the values and practices of the West. (p. 335)

However, there is more to this than simply cultural hegemony. Despite my (upcoming) commentary upon the shortcomings of biomedicine, the truth remains that, for the theoretical 20% I speak of, it is more often than not the difference between life and death, comfort and suffering, ability and disability. Barsh noted, in his evaluations of the epistemologies of traditional healing systems of Ayurveda, Unani, Traditional Chinese Medicine, homeopathy and indigenous medical systems, that "different medical traditions have different standards of evidence and ideas about the purpose, outcome, and timing of treatment by methods that may not involve pharmaceuticals, such as acupuncture or chiropractic" (2006, p. 61). Notwithstanding those instances where biomedicine has not 'caught up' with traditional knowledges in a few select areas (such as ethnobotany, cf. Plotkin, 1993) or the limited understandings of the human connections between body and mind, it currently appears that biomedicine *works* more consistently and more thoroughly

than other models. This has led, unfortunately, to a situation where other modalities are dismissed out of hand as inadequate or inferior. A cultural hegemony has descended upon health.

For instance, within Canada itself, the cultural clash between Aboriginal and European settlers' understanding of 'health' and how 'health care' was practised, historically, "resulted in a loss of traditional healing knowledge and of healers themselves" (Lalonde & Bucio, 2009, p. 957). It is only now, as self-determination has become politically possible, that we are seeing a new form of Aboriginal medicine emerging, one that combines select elements of their cultural past with components of the Western medical model. Arguably, with such efficacy comes with the opportunity to define ideas such as 'health' for a group, and ostensibly can serve as a form of community (and individual) empowerment. This hybridisation is likely to be the model for health of the future as cultures and understandings continue to come into contact with one another.

Another understanding of 'health' comes from the field of health economics, and was best captured in the phrase "longevity without incapacity" (Dormont, Martins, Pelgrin, & Suhreke, 2007, p. 4). Health, in this instance, was something that a) allows greater productivity, and b) costs less money for society (though the dollar costs can be deferred to the individual, depending upon the healthcare economy of the nation in question). This, in turn, led to greater economic gains for all concerned. In the authors' words:

Better health positively impacts labour supply, notably through a longer life expectancy, and healthier individuals can reasonably be assumed to produce more per hour worked...a longer life span will also encourage people to acquire more education. Good health results in more educated and productive people. Healthier

individuals (or the total population) are more willing to undertake investment, which in turn promotes growth. Finally, a substantial share of health spending being devoted to finance R&D, it contributes to innovation and growth. (p. 4)

Note that this understanding of health didn't seek to define itself based on what the individual was or wasn't, but rather what the individual *did* or could do. In this respect, it was tied more closely to notions of health literacy than might, at first, have been apparent. It would be naïve, however, to accept Dormont et al.'s overly simplistic depiction of the relationship(s) between things like longevity and education. It is not altogether clear that longevity leads to more education, or that people invest more as a result of longevity: This leads, ultimately, to Jacalyn Duffin's observation that the definition of health is both "elusive and circular" (2005, p. 27).

Health as a 'resource', a form of capital that extends beyond the production-centric definition of health economics, is a potentially useful definition as well. As envisioned by Williamson & Carr (2009), health was as much a resource for everyday life as is education, skills or literacy (p. 112). This definition did not provide delineation of what health was or wasn't: rather, it spoke of what a state of 'health' allowed an individual to do – whether it was an end unto itself (enjoying quality of life in the physical and psychological sense), or a means of attaining something beyond the intrinsic state of 'health'. I suspect that such an understanding is much closer to the intent of the Ottawa Charter (1986), and subsequent World Health Organization [WHO] publications and programs.

Lalonde & Bucio (2009) offered an intriguing (if somewhat incomplete) definition of health, one that avoided the unattainability of the WHO's 'complete-ness': "Health is not merely the absence of disease; it is intricately linked to culture, religion, social status,

and economic welfare” (p. 962). In other words, health was, of necessity, contingent. What was valued defined all else – and it is this realisation that will help us understand the emerging notion(s) of health literacy better than all other approaches; and more than this, *who* defines what ‘health’ means will drive what is meant by ‘health literacy’. Dutta & Basu (2008, after Giddens, 1984, 1990) suggested a double-hermeneutic understanding of health: here,

Health becomes articulated as a context-rich phenomenon, embedded in the shared meanings and life experiences of the participants and constituted through the dialectical tensions between structures that constrain health, and human agency that seeks to transform these structures. (p. 561)

It is this balancing act that defines the primary challenges of understanding ‘health literacy’.

What remains unspoken in all of these definitions is the moveable notion of what is a fair *expectation* of our physical and mental selves – in other words, when we envision health, do we have an accurate sense of what a 30-year-old versus a 60-year-old body is capable of, all things being equal? Do we have any appreciation for what our own physical selves can tolerate in terms of pain, reduced function, exercise, or caloric intake? Do we grasp that seven-year-olds the world over are diverse, and that trying to fit them into the same category (or the same pair of pants) is perhaps an early exercise in futility? Each and every definition of health has this as a subtext, and it is this subtext, communicated through context, that will lead us deeper into the discussion.

Interlude Two: Literacy, the Word and the World

Similar to ‘health’, ‘literacy’ captures global passions, and like ‘health’, ‘literacy’ is equally ephemeral. It would probably be impossible to underestimate the importance of literacy as a concept in modern society. Seen by many as the harbinger of all things positive, literacy is one of Macedo’s “shock words” (2006) that, when used, is emblematic of good (and, as such, short-circuits critical reflection (p. 157)). For instance, it is rare to hear someone espouse (at least publicly) that literacy for all is a *bad* idea. I am certainly not suggesting that being literate (in a whole host of fashions) is detrimental. However, the meaning of literacy is neither a) agreed upon, nor b) regarded as a force for only good. McLaren believed that “Freire has revealed to us that *literacy* practices are practices of *power*” (1992/1993, p. 10, ital. added). Like health, literacy is something that is subject to cultural constructions, is personally mediated, and has the potential for hegemonic manipulation. The fusion of health and literacy into a singular phrase risks obscuring these relationships.

Since at least the 1950s, the term and the concept of ‘literacy’ have been grappled with. Even today, it carries a host of potential meanings, ranging from the basic skill set of reading and writing all the way to a critical literacy, one where the very act of reading and writing is problematised (UNESCO, 2005). Today, there is an awareness of literacy as both a product and a process: it is more than just something an individual possesses; it is something that is part of a larger societal system. It is a membership card for both an individual into a group, and a group into a collection of groups – for instance, women into larger society, and developing countries populations in the global economy.

‘Literacy’ is a very interesting word, one that defies a concrete, consensual definition in the post-modern context (and this speaking purely in the English milieu). No longer simply “reading and writing” in the dominant language, literacy has come to have myriad meanings:

Terms such as *literacies*, *literacy practices*, *basic literacy*, *initial or advanced literacy*, *functional literacy* and *post-literacy* are used with widely different, and sometimes unclear, meanings in policy, programme and academic contexts. Indeed, these terms reflect the multidimensionality and complexity of literacy and underscore the urgent need to go further beyond the traditional dichotomy of “literate-illiterate.” (UNESCO Institute for Lifelong Learning, 2013, p. 20)

What is meant by ‘literacy’ is obviously critical for the purposes of this study: after all, how can I explore ‘health literacy’ if I do not have a clear idea of what is *meant* when ‘literacy’ is used? Moving through the literature review for health literacy, it will become apparent that there exists within the field a range of understandings of health literacy commensurate with the range of understandings of literacy. In many ways, ‘health’ is merely a modifier (UNESCO, 2005, p. 150) that points towards a context-specific usage of literacy, and that is the manner in which it will be used in this work.

In 1992, the National Adult Literacy Survey was conducted in the US (Kirsch, Jungeblut, Jenkins, & Kolstad, 2003), followed by the International Adult Literacy Survey in 1994 (Kirsch, 2001). Canada was among the countries that participated in this household survey designed to measure participants’ (ages 16-90 in Canada) literacy across three task categories. The results were sorted into five (5) levels: Levels 1 and 2 were considered functionally illiterate and functionally literate, respectively, but below the

necessary achievement level to function well in Canadian society (Sum, Kirsch, & Taggart, 2002, p. 5). Roughly 48% of Canadians fell into this category: a further 20% were in Level 5 (essentially, highly literate in a generic sense), leaving the remainder distributed within Levels 3 and 4.

But what does this mean? Looking at the task categories, prose literacy encompassed reading, comprehending and extrapolating from texts like newspapers, poems, and stories; document literacy included deriving information from forms, maps, labels, and anything else considered ‘noncontinuous’; and quantitative literacy consisted of the ability to work arithmetically with numbers embedded in text, such as banking, nutrition labels, or ordering items. Does this capture what literacy, in a society, requires? Is there anything missing from this framework?

Early in my study, my understanding of ‘literacy’ (within the purview of health literacy) was closely akin to the ‘reading and writing’ concept of literacy; this was a result of my grade school experiences with a (limited) notion of literacy. It wasn’t until I began my graduate work that I became increasingly aware that

Literacy is no longer seen as an ability that is developed during the early school years, but is instead viewed as an advancing set of skills, knowledge, and strategies that individuals build on throughout their lives in various contexts and through interaction with their peers and with the larger communities in which they participate. (Kirsch, 2001, p. 4)

Kirsch also went on to note that “we live in a technologically advancing world, where both the number and types of written materials are growing and where increasing numbers of citizens are expected to use information from these materials in new and more complex

ways” (p. 4), an incredibly important concept to remember when evaluating notions of (health) literacy. Upon reflection, these observations seemed self-evident. However, it would be disingenuous to claim that I started with such a view.

Understood in this manner, those individuals and behaviours that are operating outside the literacy expectations of a given situation are then classed as ‘illiterate’. However, being illiterate can mean a number of things, and it serves my purpose to share Kevin Harris’ vision. He tells the story of attending an orchestral performance, and while reading the program notes on the composition of the concerto, prepared by the conductor, is struck:

I read that, and find to my paradoxical astonishment that the very act of reading it determines my illiteracy. I cannot understand what is being said. I do not know what I might say as a response. I have been excluded from the discussion. And yet this is a concerto I listen to often, which I love dearly, which I knew well enough to hum from beginning to end, and which I thought I could discuss with some authority and confidence.

My problem is that [the conductor] has set his commentary on the concerto within a field of discourse that is beyond my informed understanding. The discourse is not totally foreign to me, or meaningless. If it were I could more easily ignore it, just as I can shrug off a nearby conversation in Sanskrit or Old Icelandic of which I do not understand a single word. No: the problem is that the discourse is being conducted in terms which [sic] I at least recognize, and which, more importantly, I recognize to be legitimate...But it does not make sense to me. Thus I am ignorant. Worse; I am ignorant, illiterate, and consequently impotent – and all

because I have not been sufficiently initiated into a field of discourse which I recognize, and which I concede to be legitimate. (1993, pp. 58-59)

I have been, many times in this study, in Harris' position. I have felt the bafflement and (I'll admit) horror of *not being able to make sense of something*. Something I *knew* was important and legitimate, but still outside my purview. I lacked his "informed understanding". And it was in those moments that I leveraged skills such as my *critical 'media' literacy* to find contextual clues to help me vanquish my illiteracy.

Here lie the inherent dangers with blanket notions of health literacy: It does not seem sufficient to understand literacy as a task that requires *prose*, or *document*, or even *quantitative* literacy (although all are important): there is also a requirement for *contextual* literacy. Even in situations where we recognise (as did Harris) the *validity* and *value* of the context, we may be operating outside the parameters of the field, and are, therefore, *illiterate*. And it remains to be seen whether we possess the ability, the access, or even the desire to change that position.

Therefore, the opposite can be just as true: we might be fully aware of the 'recommended' behaviour (the 'literate' behaviour), we might even be able to regurgitate the right responses, but ultimately we choose something other than the authorised action(s). This can be overt, and it can be covert, resistance or refusal. Nussbaum (2000) took up something of this challenge when speaking of 'universal values', asking, quite rightly, "Where do these categories come from...how can they be justified as appropriate ones for lives in which those categories themselves are not explicitly recognized?" (p. 35). She observed that,

...when we think of health...we should distinguish between the capability or opportunity to be healthy and actual healthy functioning: a society might make the first available and also give individuals the freedom not to choose the relevant functioning. (p. 14)

In this understanding, the maintenance of those features of society that allow for the possibility of health (or any other civic feature) are supported, but they do not lead to the *inevitability of state-defined health or health literacy*. There becomes, within such a model and understanding, room for alternative viewpoints and actions.

Jahan (2001) noted that, in a study of health literacy and the prevention of diarrhoeal disease in Bangladesh,:

The fact that many recipients of health education...can recite the information they have received is often cited by health professionals as proof of program success, and there is an assumption that by having the information, individuals will then take steps to improve their health. (p. 286)

Jahan further pointed out that this was not what happened: sometimes the health literacy programs fell outside the cultural context of the participants, sometimes there were systemic barriers, sometimes the ability to repeat words didn't mean a person understood, and sometimes people simply did not want to engage in the 'health literate' behaviours prescribed. It is possible to read such events as illiteracy, but it is also possible to regard them as acts of critical literacy. Whatever the reason, things like agency, perspective and power are commingled, and within the realm of (health) literacy, a response is required – in fact, it is demanded.

Critical theorist Henry A. Giroux, in his introduction to Freire and Macedo's *Literacy: Reading the word and the world* (1987) problematised the idea of illiteracy, stating

Within this dominant discourse [unitary Western tradition], *illiteracy* is not merely the inability to read and write, it is also a cultural marker for naming forms of difference within the logic of cultural deprivation theory. What is important here is that the notion of cultural deprivation serves to designate in the negative sense forms of cultural currency that appear disturbingly unfamiliar and threatening when measured against the dominant culture's ideological standard regarding what is to be valorized as history, linguistic proficiency, lived experience, and standards of community life. (p. 3)

If, in fact, Giroux is correct, then *any* type of literacy is *cultural* (which is to say *contextual*) literacy, and that includes health literacy. That is, what we now think of as 'literacy' is really simply a form of literacy that is geared towards a particular language, being used in a particular way, in a particular culture (or subculture), in a specific place, at a specific time.

Given these basic observations, how might we conceive of 'literacy' for such a study of the Western middle-class experience with 'health literacy'? Nutbeam (2000) provided a useful framework for beginning to think about this in his adaptation of Freebody & Luke's (1990) work. In his exploration of health promotion and education, Nutbeam proposed three levels of 'health literacy' (with a fourth category for 'illiteracy'): functional, interactive and critical. He acknowledged that these were not new concepts – what was

new was the contextualising to health. UNESCO (2005), for instance, still utilises its 1978 definition of ‘functional literacy’:

A person is functionally literate who can engage in all those activities in which literacy is required for effective functioning of his [sic] group and community and also for enabling him [sic] to continue to use reading, writing and calculation for his [sic] own and the community’s development. (p. 30)

So, what is unique about Nutbeam’s contribution? Perhaps what can be learned from Nutbeam’s particular framing of literacy is that, with his ‘levels’ (which actually aren’t firm levels), it provides those encountering the concept a mental map of how a person might progress in *using* her or his literacy skills. However, even that can be problematic, for at least two reasons. First, it leads one to believe that there is a sequencing or scaffolding of literacy development (from the functional through to the critical), which is not strictly true, as we will examine in Act IV and V. Second, because it implies a certain level of *choice*: the choice to use literacy skills goes hand-in-hand with the *opportunity* to use such skills. This is where we cross over into Freirean notions of literacy, and the alternate meaning(s) of ‘critical’ in ‘critical (health) literacy’.

How Nutbeam envisioned critical (health) literacy was not, strictly speaking, how critical literacy theorists understood (and still understand) the term (even if we take the ‘health’ out of the phrase). In Willinsky’s (2007) words

...critical literacy can be said to owe a striking debt to the twentieth-century legacy of Critical Theory [which] was given to intellectual acts of resistance that were intended to undermine the increasing regulation of life, in an effort to create a

counter-weight to what was seen as the deception fostered by political regimes that were sustained by the culture industry. (p. 1)

Nutbeam's critical (health) literacy does, certainly, advocate a certain amount of awareness of and innovation in the face of societal challenges (such as poverty, illiteracy, gender equality, technological encroachment, and so forth), but there is little evidence that he aligned his usage with Anderson & Irvine's view of critical literacy as something where one "analyses how social texts and discourse practices are constituted to maintain inequality and how the consensus to maintain this inequality is achieved" (1993, p. 91).

Apple (1993) had this to say about what our goals around literacy should be:

Our aim should be to create not "functional literacy", but *critical literacy, powerful literacy, political literacy*, which enables the growth of genuine understanding and control of all the spheres of social life in which we participate. (p. 193)

While educators, policy makers, and medical professionals working with the idea of health literacy are faced with an exponential increase in both the number of individuals affected *and* an increase in health information's load and complexity, individuals themselves are equally, or perhaps more so, affected by the requirement to find and digest potentially vast amounts of information, from diverse sources, of increasing intricacy, with very little educational support or time in which to accomplish such tasks.

This kind of literacy becomes progressively more about *access to* these voluminous information sources, both in terms of *finding* them as well as *comprehending* them. This sort of literacy almost acts in a gatekeeper function: those that have access to (in the varying meanings) the knowledge are privy to the dominant discourse, while those that cannot access this information are oftentimes with little recourse within the "reality which

must remain untouched” (Freire, 1970/2008, p. 94). However, it would be inaccurate to think that that means these individuals have no access to health practices or care: rather, what is being said is that these individuals are operating outside the authorised texts – culturally dominant biomedical texts. As a result, they are at risk of being labeled ‘illiterate’.

There is one other aspect of critical literacy that I wish to broach: critical *media* literacy. It may have been sufficient in times past to base such work as I am attempting on print-based texts; however, in the postmodern era the technologies employed in the media far surpass such a simplified understanding of literacy. Steinberg & Kincheloe (1995) call my children and me “children of hyperreality” (p. 3). Further, they call upon us to “not simply develop the ability to interpret media meanings but also the ways...[we] consume and affectively invest in the media” (p. 2). This will, effectively, redefine our praxis, understood by Sholle & Denski as the “self-creative activity through which men and women create (make, produce) and change (shape) the historical, human world and themselves” (1995, p. 11). I came of age during the mass cultural transition to an Internetted-world, and my children know of no other form of existence. It thus behooves us to interrogate how such a ‘reality’ feeds into our concepts of knowledge and literacy; particularly within the nexus of health and wellness, the opportunity to engage with critical media literacy is profound.

Interlude Three: Terms of Use

Surveying the linguistic and conceptual landscape of Western discourses on ‘health’, a number of terms and phrases arise, such as hygiene, sanitation, public works, public health, health promotion, health education, health communication, health beliefs,

determinants of health, wellness, wellbeing, disease, illness, treatment, screening, risk, prevention, medical, clinical, curative, critical, traditional, holistic, alternative, and, perhaps most recently, health literacy. This list is unlikely to be exhaustive: what it does point to, however, is the depth and complexity of the ever-evolving notions and words we use to talk about and enact our ideas around ‘health’ and ‘care of health’ (healthcare). In fact, the very attempt to present a linear discussion is deeply problematic, at least to me: over time, I have become painfully aware of how intricate and baffling the various terms, histories, and connections are, and I only embark on this section with a deep sense of hesitation. On one hand, I am aware that *some* contextual backstory is required; on the other hand, I also know that no words I write can possibly do justice to the subject.

Health literacy might be, at least terminologically, new to the scene, but it has been conceptually creeping up upon us for quite some time. There are a complex set of interactions that underlie what health literacy is, can be, is related to, and how it is manifested. Tracing back through time, two significant lines of thinking can be followed in the relationship we have had to ideas of health and healing that are directly tied to current notions of what health literacy is: in Stark’s (Stark, 2006) words, they are ‘curative’ and ‘preventive’. Simply put, ‘curative’ denotes actions intended to return a person to ‘normal’ (obviously, ‘normal’ is a contestable notion). ‘Preventive’ refers to avoiding the movement away from the norm in the first place. In our current Western context, ‘curative’ is most clearly associated with the medical establishment, while ‘preventive’ aligns more closely with actions taken by individuals and/or actions taken by governing bodies. Both are closely tied to the idea of Progress (Burnham, 2005).

There is room, I think, for a third notion: healing. This distinction is perhaps captured most clearly in the following chiasmus: one can be healed without being cured, but it also possible to be cured without being healed. Many cancer survivors, for instance, are part of a ‘remission society’ (Frank, 1995, pp. 8-13), one where, though the cancer has been removed or destroyed, the damage to the psyche and the ongoing awareness of the *possibility* and *likelihood* of the disease’s recurrence are a burden that is lived with for the remainder of life. Similarly, numerous non-traditional health interventions (many understood as working with the spiritual, mental, psychic or emotional components of the human health condition(s)) have been shown to ‘heal’ individuals who have not necessarily been cured. Exorcisms in the Catholic faith serve this purpose; meditations, prayer, journaling, cultural practices such as nutritional interventions, all of these fulfil the notion of healing a person (who may or may not be ‘cured’ by biomedical standards). Of course, there is perhaps a distinction that needs to be drawn between those things recognised as ‘illness’ or ‘disease’ in biomedicine (and thus treatable or curable) versus those things that are ‘healed’ in these other manners, but nonetheless healing exists as an idea separate from prevention and cure-proper. This is a thought we shall return to in later sections.

Buried within these ideas are further concepts, such as ‘expert’ and ‘layperson’ (or citizen): whether that ‘expert’ is a shaman, a doctor, or a midwife, the idea is that someone holds more knowledge and/or experience than another, and is therefore more ‘qualified’ to guide, enact, command, prescribe, undertake, and so forth, some health-related action upon another. There is certainly evidence that those with knowledge and/or experience (or the perception thereof) can be exceedingly protective of their status, with guilds, societies, and associations, offering in-group and out-group designations to the various members of a

community (Burnham, 2005, p. 3; Charles et al., 1997, p. 386). The expectation, of course, is that those in the in-group will be valued in some way by the out-group, at least when it comes to matters of health care. By this, I mean that persons such as doctors will hold an esteemed status, something that sets them apart from the ‘average’ person, in terms of their knowledge and skill’s value. In Western contemporary situations, such knowledge and skills manifest as the authority to diagnose, prescribe, order testing, treat, and conduct other technological interventions. Patients have no such status (at the very least, in no formal, authorised sense).

At the turn of the 20th century, the majority of babies in Canada were born in homes with the help of a midwife (Mitchinson, 2002). Pregnancy and childbirth were not viewed as a medical event – they were merely something that happened to a woman, often many, many times in her life, and midwives were frequently onhand to assist with the process. As the most experienced members of the community in matters of parturition, midwives held the status. Little more than anecdotal stories exist to validate claims that midwives were as successful as the emerging medical practice of obstetrics, but there seems to be a current groundswell (is it misplaced nostalgia?) that characterises midwifery as more pure, natural and, ultimately, ‘good’.

The advent of the germ-theory (and the entire scientific revolution), and the potency of the disease model of health that came with it, led to a distinctly biomedical turn in health and the care of pregnancy and birthing. Over time, as the ideas solidified into dogma, and the push to standardise, credential, license, and such, took over, the result was ‘hospital-trained’ doctors – nearly always male and of European descent. In order for such individuals to ‘make a living’ as a doctor, they needed to convince women (or at least the

family member calling those shots, cf. MacKay (2007), – the most likely ‘repeat customer’ – that they were safer, that their babies would be safer, being delivered by a medical professional (Friedan, 1963; Mitchinson, 2002; Schwartz, 2006; Wolf, 2001). The hegemonic discourse went as far as attributing the spread of puerperal fever (childbed fever) to “rough usage by an ignorant midwife” (Schwartz, 2006, p. 201), when there was ample evidence that the spread of this bacteria was due to dirty hands and dirty instruments (Schwartz, 2001, pp. 242-245) used by the doctors, *not* the midwives. Returning to the 80/20 rule, and the idea of infant mortality, the demographics certainly seems to indicate that early childhood death (mother and child) has decreased since the medicalisation of pregnancy and childbirth (Canadian Museum of Civilization, 2010; Conference Board of Canada, 2012). However, I do return to McKeown’s observations, and question whether, strictly speaking, medicinal interventions impact more than the 20%, with public health measures speaking for the remaining 80% (and how we categorise ‘preventable death’).

In this one example, who is the expert? Is it the person who *is* the expert, or the person who *says* that he or she is the expert? What role does societal power have in these definitions? How do we measure such things? We paint our current context as progressive; that is to say, we assume that our present-day knowledge and technology is ‘better’ than that which preceded it, but one needs only reflect upon the contemporary debates on fluoridation to consider things might not be as clear as that (Adams, 2011; Carstairs, 2010; Fawell, Bailey, Chilton, Dahi, Fewtrell, & Magara, 2006; Levy, Broffitt, Marshall, Eichenberger-Glimore, & Warren, 2010). For instance, Calgary has had six plebiscites, 1957-1998, on the question of fluoridation – as in, ‘do we add it to our water supply or not?’ (the first four answered ‘no’). Despite the bodies of evidence coming from

the medical and dental communities in Canada and abroad (Australian Government: National Health and Medical Research Council, 2007; McLaren & McIntyre, 2011, p. 21), and despite affirming the addition in 1989 (and re-affirming it in 1998), in early 2011 the Calgary City Council voted to end the addition of fluoride to the city's water supply (Calgary already has abundant fluoride coming from its natural water sources). Each time this debate has flared, well-researched and organised groups have stepped up in both camps. Where does this leave the expert versus layperson contest?

Furthermore, returning to the lens of curative/preventive, how might we understand the midwives' position versus the doctors' position? In the contemporary context, I'm sure that the vast majority of doctors would feel that their work is *preventive* in nature – that is, they *prevent* something 'bad' from happening to the baby or the mother, and it is perhaps hard to fault that position. I would certainly be a hypocrite if I did. However, it is possible to see their work as *curative* in nature, given the idea that pregnancy is medicalised, and it is surveilled, and both indicate a move towards the 'not normal'. Again, there is a range of understandings and expectations at play here, and a Western pregnancy is rife with lists of 'healthy pregnancy' factors that are presented to the newly (potentially) 'not normal' body of the woman.

There are a number of additional ideas lurking that bear consideration, namely public (population) health, health education, health communication, and health beliefs. Public health is driven (increasingly) not just by ideas such as public works (those factors related to hygiene/sanitary conditions of food, water, waste disposal, and the body), but also by *determinants of health*. These are sometimes referred to risk or protective factors (Shah, 2003; Yuill, Crinson, & Duncan, 2010), but in the main, they refer to those things

that affect both a person's ability to make healthy choices, and those biological, environmental, and systemic factors that make the range of choices limited. We know that maternal literacy rates are tied to child wellness outcomes, but that that literacy has nothing to do with the presence or absence of a clean water source or soap for washing. We also know that safety concerns in inner city neighbourhoods often prevent children from playing outside, no matter the public health rhetoric. So, while understanding determinants of health is *necessary*, it is not *sufficient*.

Public health, then, as envisioned and operationalised by governments and non-governmental leadership, is constructed through policies, procedures, actions, systems, infrastructure and so forth that aid and abet 'healthy' living for the populace – essentially preventive maintenance. Leaving aside the obvious economic benefits to society of a productive (and therefore less costly) public, public health initiatives serve to (ostensibly) make healthful choices easy, by providing guidance and information, and removing systemic barriers. How close to reality these dreams come remains to be seen.

One of the prime movers in the public health universe is the concept of health education (which can easily be coalesced with health communication from the standpoint of *currere* or critical theory). Health education (and by this, I am referencing 'authorised' health education) serves to pass messages related to health and health care (not to mention the systems that can be accessed for these things) to the citizenry. While the methods and channels have vastly changed and expanded over the duration of the public health movement (ie. the development, spread, and now-near-ubiquitousness of digital technologies), the objective is the same: provide information/education to laypersons that is intended to influence health beliefs (and therefore health actions). It is not designed to

inspire critical thinking. In this manner, such ‘health education’ serves as a culture-making device: a way of moving the larger part of the population (or the target market, in marketing parlance) towards a collective belief (and oftentimes, action) around some notion. Witness the handwashing movement: from signage in public restrooms, to the advertisements rife with products to clean and sanitise hands, to the programs built into the school curriculum, the ‘education’ around this basic hygiene step has permeated our collective intellectual space – but few know Ignaz Semmelweis’ name or story.

Turning our attention to the curative thread, we can see many of the same principles in operation. Medical professionals have positioned themselves as the purveyors of both quality and quantity of life: and they have successfully argued that such things are a right as a human being (in Canada) or at least a right for those who pay (in the US). Medical care is perceived to be something that is offered in enlightened countries to enlightened populations (witness the current discursive civil war being fought in the US over ‘Obamacare’). But it is a little more complicated than that: it is also what is available to those who can *pay* (either as a country, as in Canada, or individually, as in the US). Those who can pay have ‘made it’ – they are not morally defective as a result of their poverty or in some other (unmeasurable) way *less*. It is something sought after by communities around the world. It is a marker of success and civilization.

There are three basic functions of clinical care: curing sickness, healing injury, and easing the collapse of human physiology (as in aging). Of course, there is some degree of overlap, and there is also some degree of personal nuance – for instance, there are injuries that result from ‘wear and tear’, yet by being medicalised they are moved (often unsuccessfully) into the ‘healing injury’ column (e.g. spinal degeneration) or ‘curing

sickness' (e.g. Alzheimer's). Age is a factor – we are far more likely to regard a 40-year-old with spinal degeneration as someone with an 'injury' than as someone approaching the functional end of their back's life (at least in a Western context). Cultural understandings of what is even considered 'sickness' can be changeable, such as the notion of 'toas', a Cambodian affliction that corresponds to "postpartum wrongdoing" (Tea, 2010, §6 para. 1-3). Incorrect 'treatment' during *sor sai kchey* (one-three months postpartum) (ibid, §3 para. 1) can result in a lifetime of somatic and psychiatric disorders for the childbearer. We have an ever-sliding mental scale of what is acceptable versus unacceptable when it comes to 'health' – and that continues to change over time and space. Historically, sickness was a way of dying; now, it is very often a lifestyle, or a way of living (cf. chronic illness, Herzlich & Pierret, 1985).

This is, of course, directly attributable to our *other* major expectation, that of the nature and timing of our eventual expiration. North American (Western) biomedical culture regards death, in the greater part, as a non-optimal (though admittedly eventual) outcome. Further, if said death occurs younger than older, more painful than less painful, more incapacitated than less so, it rankles the contemporary Western mindset (at least the dominant one). These are indications that we *expect* more life, and those expectations are placed squarely on the doorsteps of the curative professions (i.e. the medical establishment). They are placed there because the scientific model, and the medicine and technology that have arisen from it, are so damn effective, whether we like it or not. But, as Baron reminds us, "clinical practice occurs at the intersection of a patient's need and a doctor's power and impotence. We, my patients and I, do the best we can" (1990, p. 28): doctors are only as 'powerful' as science, technology, the medical establishment, culture,

society, economics and personal ability allow them to be. The exact same can be said of the patients.

When you visit a physician in the the curative/clinical realm, you are entering into a (powerful) subcultural system, where there are various gates, pathways, roadblocks, and none to few bogeymen. There are only a few entry points: by ‘appointment’, by ‘referral’, by ‘walk-in’ and by ‘emergency’. These entry points are closely guarded: appointments are generally made through clerical staff who control access to the medical professional; referrals are gained through the point-of-contact (typically a general practitioner) medical professional; walk-ins are managed on a first-come-first-served basis (and are constrained in terms of time and access to consistent care); and emergency access is gained through a triage process controlled, characteristically, by emergency/triage nurses.

In the general practitioner/family medicine encounter, there are essentially two types of ‘appointments’: one is the ‘check up’, and the other is for something that is ‘wrong’. The first is to make sure everything is ‘normal’ (preventive), the second to address things that are ‘not normal’ (curative). There is no appointment for ‘healing’ – this is, of course, assumed under the heading of ‘curative’. Once a person makes an appointment, she or he is magically transformed from being a person to being a patient. And while it is the individual who makes the appointment (or that individual’s designate), it is the doctor who decides whether the person is properly categorised – a preventive appointment can become curative when something is ‘wrong’, and a curative appointment can become merely preventive when it is deemed *nothing* is wrong. Mind you, the ‘preventive’ designation is likely in the eye of the patient, not the doctor: it is more than likely the doctor will regard the time spent as wasted, especially if the physician in question

is a ‘specialist’ (but you will be billed, never fear). The exception to this is when there is, in fact, something *wrong*, but through inadequate testing, knowledge, diligence, information, or technology, that wrong thing is not found – perhaps until later, too late or never.

Specialists are generally the hardest to reach: the larger majority will only book appointments with a referral from a fellow physician (like a family doctor), and frequently the appointments available are in the mid- to far-distant future. Two years is not unheard of (despite the omnipresent ‘reduction of wait times’ rhetoric), and this is attributed to many factors, depending upon who you ask. Shortage of specialists, inappropriate usage of specialist services (like improper referrals), shortage of facilities and technologies (like access to operating rooms and MRIs), and reduced hours are commonly cited. Little sympathy is available to a stressed patient (or loved one) who fears the worst, yet must still wait months, or more, to have a situation assessed by an ‘expert’. And how a patient is triaged (and whether the patient is financially covered or pays out of pocket) is decided under the ever-changing rubric of ‘medically necessary’: because what is deemed medically necessary is not contained within the Canada Health Act, it is left to the prevailing opinions of a host of individuals (at least in Canada) at the provincial/territorial level. What is medically necessary in one system, or to one medical profession, is not necessary viewed similar to or with others. Some commentators have even held that a

more broad approach [be taken] when considering what an individual patient needs, and say the health system should fund whatever improves a patient’s health, without any rules or lists of treatments approved for funding. This could mean funding alternative medicine or even paying for things that are not medical

treatments at all, such as housing or education. (Commission on the Future of Health Care in Canada, 2002, p. 8)

This last part is obviously much closer to a social justice approach, though unlikely to gain a lot of traction in the near future, given the magnitude and expense of such an undertaking. Again, ‘medically necessary’ is a matter of perspective.

Even these relatively simple explanations hide the complexity inherent in the relationships and nuances that abound in the system. For instance, on more than one occasion I have been counselled (by medical professionals, no less) to essentially harass other medical professionals’ clerical staff into getting an earlier appointment with a specialist, under the auspices of “the squeaky wheel gets the oil” (in this case, ‘medically necessary’ might come down to being sick of my harassment). Obviously, there are all kinds of power issues in such transactions: the power to decide, the power to influence, the power to say ‘yes’ or ‘no’. And what about the situation wherein the specialist codes a procedure as ‘medically necessary’ for insurance purposes, because either the patient can’t or won’t pay for it out-of-pocket? Where does this fall?

Then there are the encounters with medical professionals necessitated by emergencies – those moments when you either a) can’t make a regular appointment (like after you’ve had a crash or a heart attack) or b) don’t want to make a regular appointment (like when you’re bleeding profusely or it’s a Saturday or you don’t have a family physician). These are the most clearly connoted ‘curative’ exchanges, at least in theory. In those instances you are arguably turning your self over to the reliable hands of experts that will do their utmost to ‘make you better’, or at least keep you from dying. It’s pretty difficult to argue a preventive stance in a truly urgent or emergent situation.

There are, of course, other clinical encounters that occur that are not with MDs, such as public health nurses, diabetes educators, chiropractors, dentists, optometrists, lab technicians, physiotherapists and diagnosticians. Those that have ‘Dr’ in front of their names can offer treatment and advice: those that are working the machinery (like testing your blood or your body) are gathering data, and can’t even tell you what the data says (or at least, are not *authorised* to tell you). Whether this has more to do with the professionalisation of certain levels and types of medicine (and the authority conferred by licensure), or inherent features of the profession, is negotiable.

All of these notions, terms, and histories, play into the creation of health, and they all operate consciously and subconsciously to form what health literacy is and can be. Trying to coalesce such complexity into one simple term – health literacy – is *anything* but simple.

Despite the increasing prevalence of ‘health literacy’ discussions and policy at the government and institutional level, and the concept’s impact on day-to-day life, it’s unlikely that the average individual is familiar with the term. There is, as yet, no “linguistic bridge” that has been built between what is being crafted at the practice/policy level and how those new ideas are impacting the individual. It is far more probable that ‘public health’ and maybe even ‘health promotion’ rings a bell. Guesses can be made at the meanings of ‘health communication’ and ‘health education’, but as for a firm grasp (or, for that matter, a desire to have a firm grasp) at their meanings, well, that’s far less realistic.

Part of the reason why this might be the case is the media’s inculcation of certain terms and ideas at the expense of others in the popular lexicon. Health literacy isn’t

particularly sexy, and there is certainly no real poster child for the concept. The age of the term is also likely to be a factor: public health and health promotion have been part of the Canadian social marketing and policy landscape for a much longer time (Rutty & Sullivan, 2010), in the order of many decades. Health education and health communication have never properly been the purview of the citizenry-proper: rather, they have existed (and continue to do so) as tools for conveying specific messages about the prevailing notions around healthful behaviours and thoughts (cf. Feather, 1984). The internet has offered up ample opportunity for the layperson to wax philosophic (or even pretend to be knowledgeable) on matters of health, but those are unauthorised discourses (which does nothing to help the average person sort through the general mess).

Intrinsically tied to our beliefs and actions towards *creating health* is our presiding definition of *health* itself, which we have already discussed. Far from being definable universally, it is instead itself subject to the mindset of the age (Foucault, 1972), and it is the changing mindset(s) that is/are most evident when looking at the terms ‘health promotion’ or ‘health literacy’. For instance, ‘Public Health’ started with ‘Public Works’: public works are those components of infrastructure developed for the betterment of society – the ‘sanitary idea’ (Rutty & Sullivan, 2010) that involved clean water, clean food and clean people (to go along with general ‘clean living’). It would be a mistake, however, to ascribe this ‘betterment’ to a sense of social justice. Admittedly, there were advocates and health crusaders who certainly were operating out of a sense of moral obligation, and their efforts resulted in patchy, inconsistent public health. With governments’ realisation that the urbanised, industrialised populations that were increasingly the norm in the Western world would be more productive, and cost *less*, by being healthier, and that

healthier was directly tied to *cleaner*, then the true impetus for public works became apparent.

However, such institutional actions can only carry health so far: there comes a point when it is more efficacious to convince the individual to take action. Scheper-Hughes & Lock (2006) perceived that

In our own increasingly “healthist” and body-conscious culture, the politically correct body for both sexes is lean, strong, androgenous, and physically “fit” form through which the core cultural values of autonomy, toughness, competitiveness, youth, and self-control are readily manifest (after Pollitt, 1982). Health is increasingly viewed in the United States as an achieved rather than an ascribed status, and each individual is expected to “work hard” at being strong, fit, and healthy. Conversely, ill health is no longer viewed as accidental, a mere quirk of nature, but rather is attributed to the individual’s failure to live right, eat well, to exercise, etc. We might ask what it is our society “wants” from this kind of body. (p. 308)

It is interesting to note that this shift towards what ‘health literacy’ (that is, the state where you know what “work hard” means for your culture’s concept of health) “wants”, at minimum, is a less costly and more productive populace. From the standpoint of mothering, it “wants” mothers to both “work hard” on behalf of their children’s health *and* instill these mores into children for society’s future benefit. It wants patients to work at recovery as hard as required to return to ‘normal’. Here is where we crossed into the waters of health literacy.

Health literacy is the perfect example of the crystal I spoke of earlier: It is merely the latest tilt in the exploration of the relationships between health, illness, wellbeing, medicine, technology, economics, agency, power and politics, and going variously by the names public health/public works, health promotion and health education, but it does not represent something *new*. It is questionable as to whether it even represents *progress*. Whose role it is to define ‘health’, ‘health care’, ‘patient’, ‘health care provider’, and so on, is a quandary, and each culture, including the Western, North American culture, comes to terms with these notions over and over again: the tensions between expert and layperson opinion and practice has (and is) continually adjusted in light of shifting knowledge, socioeconomic position, and education, among many other factors. Even such role-labels as ‘expert’ and ‘layperson’ are problematic: to label an ‘expert’ and a ‘layperson’ is to set up a binary, and it is unclear whether, in most cases, such a dualistic relationship exists. It is, perhaps, more useful to think of these relationships as existing in a web, whereby each person’s relative position changes based on perspective.

scene iii: Health Literacy Grows

The common account holds that the first use of the term ‘health literacy’ was by Symonds in 1974, though, by Tones’ (2002) assessment, the usage had nothing to do with the current conception and practice. The first current contemporary usage I have found appears in an article in the *Medical Journal of Malaysia*, in an article entitled “Health literacy and food beliefs among Ibans, Sarawak” (Bee, 1985; Jamrozik, 2010).

The term remained dormant throughout the 1980s, but its contemporary impetus can be traced to 1986’s “Ottawa Charter for Health Promotion” (World Health Organization, First International Conference on Health Promotion). This document

effectively launched the notion of ‘health literacy’, despite the fact the term appears nowhere in the document – and the conference (now in its 8th cycle, this time in Helsinki, Finland) itself was dedicated to furthering a health determinants understanding of health *promotion*. It is a section on the third page that seems to have created the impulse: ‘Develop[ing] Personal Skills’. The charter states:

Health promotion supports personal and social development through providing information, education for health, and enhancing life skills. By doing so, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.

Enabling people to learn, throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential. This has to be facilitated in school, home, work and community settings. Action is required through educational, professional, commercial and voluntary bodies, and with the institutions themselves. (p. 3)

The emphasis became one of developing skills in individuals (and communities, as in community capacity building) that would lead to *action* that facilitated health. These actions were predicated on correct education (in the form of information) that would ‘naturally’ lead to individuals having ‘more choice’. Operationalised through various institutional bodies, it was realised by various *human bodies*: and the ‘choice’ was to follow the correct information, or not.

At first glance this might not seem terribly different from health ‘education’ or health ‘promotion’: however, what was originally about the public’s health (individual and collective), achieved through health promotion’s ‘health education’, became for many an

issue of awareness and reflexivity – the acts of ‘health literacy’ – the *outcome* of health promotion and health education. In 1998, Nutbeam described it thus: “A health outcome...can be defined as a change in the health of an individual or group which attributable to an intervention or a series of interventions” (1998a, p. 29). In particular, the move to outcomes based on health promotion activities was predicated on the desire to be both more efficient and effective with interventions.

The first contemporary, mainstream discussion of health *literacy* appeared in Kickbusch’s “Think health: what makes the difference?” (1997). Referencing a recent update to the World Health Organization’s ‘Health Promotion Glossary’ (which actually *hadn’t* been published yet, but that she worked on closely), she stated:

In the new version of the health promotion glossary we have introduced the term ‘health literacy’, meaning it to widen what in the Ottawa Charter we had called ‘developing personal skills’: information and knowledge on health, understanding the social components of health, ability to negotiate the environment, understanding and weighing the risks of individual and social behaviour, coping skills, caring skills, skills to use the health sector, and a shift from fatalistic acceptance of health problems towards implementation of health knowledge. (p. 268)

This is an extensive and daunting roster: It is the ‘to do’ list of a Health Promotion that seemingly identifies everything we encounter as preventive- or risk-orientated. She asked, and rightly so, “Can health literacy balance the social gradient?” (p. 268). In other words, can empowering people with respect to determinants of health *affect* those determinants, and in doing so, impact health? Or, can people take over the role that has (in recent times) been the domain of the government and the professional community?

It has increasingly been seen as desirable to place the emphasis on understanding, retention and action upon the individual, in much the same way general education expects students to learn and then display that learning. In other words, *expectations* became explicit, and with them individual onus and institutional measurement. Couching the notion in terms of empowerment, it obfuscated the very real power imbalances (among many other imbalances) already embedded in the system. Increasingly people are judged 'health literate' (or not) based upon compliance, or receptiveness to interventions designed to influence thought and behaviour: the 'tools' are available to you, if you are just sensible enough to pick them up and use them (Trostle, 1988).

The glossary of the World Health Organization (1998)¹ is the first instance of a WHO document 'officially' noting "health literacy". The definition of health literacy stated:

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment. Health literacy is itself dependent upon more general levels of literacy. Poor literacy can affect people's health directly by

¹ This is the document Kickbusch (1997) references, discussed herein on p. 59.

limiting their personal, social and cultural development, as well as hindering the development of health literacy. (p. 20)

This definition understands health literacy as something the *person has* and *does*: the extension, of course, is that health literacy (or more accurately, ‘health literate’) is something that someone *is*. This vision (and virtually all other versions) focuses on the *individual*, the “single dominant text: the centrality and sovereignty of the individual” that Shotter & Gergen ascribed to the modern Western world (1989, p. ix).

By 1998 the American Medical Association saw fit to convene an Ad Hoc Committee on Health Literacy for their Council on Scientific Affairs, though this seems to have been more a response to the poor showing in literacy skills of roughly one-third of the American population on the NALS than to the work of health promotion scholars in Australia, or the World Health Organization’s glossary. This led to the publication of their oft-cited report in 1999. Brief though this report was (a mere five pages), something must account for the slim numbers of publications pre-2000, and the over-1000 that are now accessible (Rudd, 2010). It has, effectively, created a new discourse community. Supporters of the concept of ‘health literacy’ quickly pointed out that, while ‘health promotion’, ‘health education’ and ‘public health’ shared features and a common heritage, it differed in substance from its predecessors (Kickbusch, 1997). That ‘substance’ was empowerment. Detractors argued that ‘health literacy’ was merely the *nom du jour* of health promotion – the postmodern re-branding of a known entity, perhaps enhancing its palatability for some, and certainly launching new career pathways for others (Tones, 2002), but in no way substantively altered.

Tones argued that the term ‘literacy’ has a “clear and unequivocal dictionary definition: ‘the ability to read and write; the ability to use language proficiently’ (p. 287). He took exception to its use in terms such as ‘health *literacy*’ (and, one would imagine, cultural literacy, scientific literacy, media literacy, etc., etc.), stating that so used “contributes little to understanding the skills involved” and amounts to a “kind of territorial expansion” (p. 288). He pointed out that there were already terms and concepts in use, such as research in problem-solving (cf. Gagné, 1985) and decision-making (cf. Janis and Mann, 1977), as well as Freire’s ‘critical consciousness raising’ (1970). With all of these already in play, what was the purpose of (essentially) a neologism that added nothing to conceptual clarification? he asked (p. 289). While in many ways he was right, it is very interesting to note that in the intervening years, his argument (though cited by others) has not gained traction.

Tones’ point is well taken: however, I believe there is something additional to this analysis. Health literacy differs in that it presumes to judge the individual (and the community) as ‘health literate’, and to what degree. By placing evaluation in the mix (or ‘outcome’ in health education parlance), health literacy advocates are advancing an idea where people can be assessed, and subsequently graded or, as Nutbeam (2000) says, “how we define and measure health literacy is both dictated by and influential on the content and methods of health education” (p. 263). This is a substantive difference, but not the type that I think that either party particularly had in mind.

Lest one think that questions of public health, population health, health promotion and so forth, had been resolved with the advent of health literacy, rest assured: the debate continued, largely unabated. Between Tones’ (2002) seminal editorial, “Health literacy:

New wine in old bottles?” (a spin on a phrase used in Nutbeam’s 2000 work on health literacy), Health Canada’s case study on Health Promotion in Canada² (and the subsequent replacement of the notion by ‘population health’ initiatives) in preparation for the 4th International Conference on Health Promotion in Jakarta, and Raphael & Bryant’s (2002) “The limitations of population health as a model for a new public health”, the deliberations continued. At its heart, the debate revolved around the legitimacy of health literacy as notion unto itself, and whether domains such as population health, health education, health promotion, and so forth, really accomplished the same things, without a further segmentation of the field (and the resources). In many ways this literature was stumbling around the idea of a family resemblance (Wittgenstein, 1953, p. 65), without realising it.

Episode 1: Health Literacy up to the New Millennium

Perhaps the most-cited paper of the new millennium was Nutbeam’s (2000) “Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century”. To Nutbeam, health literacy was a “composite term to describe a range of outcomes to health education and communication activities” (p. 259). This particular piece outlined his “levels of health literacy”: functional, interactive, and critical (p. 266), which have become pivotal in discussions of health literacy since its publication (and not to be confused with the five levels of literacy marked by the IALS and NALS).

Functional health literacy existed at the level of “communication of information”, including “improved knowledge of risks and health services, [and] compliance with prescribed actions” (p. 266). This is the level that clinical encounters operated at, and it is

² *This case study was prepared on the recommendation of Dr Ilona Kickbusch, the then-Director of Health Promotion, Education and Communication for the World Health Organization (WHO).*

the level at which physician-practitioners focused their energies for health literacy assessment and improvement of outcomes. *Interactive health literacy* emphasised “development of personal skills”, with the “improved capacity to act independently on knowledge, [with] improved motivation and self-confidence” (p. 266). This was more akin to individuals being able to absorb, and then act upon, social marketing initiatives aimed at health education and health promotion. *Critical health literacy* moved towards “personal and community empowerment” through “improved individual resilience to social and economic adversity” (p. 266). Critical health literacy was in play when a woman chose to enact a birth plan. It is also evidenced when a community established a ‘No Logo’ vending machine policy in schools (Klein, 1999).

Nutbeam noted that these ideas were not new, and that work had been done in these areas for years (p. 265). What was *different* at this juncture was the need for a deeper, *critical* understanding of what was occurring in the health promotion/education/literacy exchange. Nutbeam captured this notion well:

Disappointingly, the potential of education as a tool for social change, and for political action has been somewhat lost in contemporary health promotion. Close attention to the impact of public policy decisions on health, and the need to create supportive environments for health may have had the unintended consequence of leading to structural interventions ‘on behalf’ of people – health promotion which is done ‘on’ or ‘to’ people, rather ‘by’ or ‘with’ people. In turn, health education has been limited to interpersonal communication and media campaigns directed towards individual behavioural outcomes and services use. (p. 265)

He uses these ideas to connect health promotion and health education to health *literacy*. Health literacy represented the ‘by’ people component of Nutbeam’s quote – and his types of literacies were examples of the nature of the ‘bys’ and ‘withs’. While many have taken up Nutbeam’s framework, at least in terms of paying it lip service, the literature in the intervening years has shown a scarce amount of true unpacking of the ideas in a critical fashion.

Much of the initial U.S. interest in health literacy stemmed from the less-than-auspicious results of the 1992 National Adult Literacy Survey (NALS) (Sum, Kirsch, & Taggart, 2002) which reported that around 90 million Americans had marginal literacy skills, or were functionally illiterate based on individuals’ scores across three literacy tasks: prose, document, and quantitative material reading. In Kirsch’s (2001) words, “the primary reason for developing and conducting this large-scale international assessment is to provide empirically grounded interpretations upon which to inform policy decisions” (p. 1). While the NALS did not specifically address health literacy, or literacy related to health, the numbers caused physicians interested in policy questions to give pause. After all – if patients couldn’t *read*, then how was a health-care model based upon that very skill going to function adequately?

A core group of American practitioners began publishing on the topic prior to the release of the AMA’s seminal report (1999). Williams, Parker and Baker et al. (1995) compared two public hospital population samples, arriving at a definition of functional health literacy, imagining it as “...the ability to comprehend quantitative information (numeracy), which may differ from the ability to read a prose passage” (p. 1678). This is an incomplete definition, to be sure: however, their writing in this period is largely in

support of their development and deployment of the Test of Functional Health Literacy, in both English and Spanish [TOFHLA and TOFHLA-S] (Parker, Baker, Williams, & Nurss, 1995).

Baker, Parker, Williams and Clark published again in 1998, contributing a piece to the *Journal of General Internal Medicine* that investigated the connection between ‘health literacy’ and hospital admission. They recognised health literacy in the following manner:

Because of the explosive growth in the number of successful medical treatments, patients with chronic medical problems currently face tremendous learning demands. For example, a patient who was lucky enough to survive an acute myocardial infarction in the 1960s was typically discharged with only a pat on the back and wishes for good luck. In the 1990s, such a patient is likely to be discharged on a regimen of aspirin, a β -blocker, an angiotensin-converting enzyme inhibitor, and possibly a low-salt and low-cholesterol diet and medications to control hypertension, diabetes, and hypercholesterolemia. A patient’s ability to learn this regimen and follow it correctly will determine a trajectory toward recovery or a downward path to recurrent myocardial infarction, disability, and death. (p. 791)

They went on to define health literacy explicitly as “the ability to read and understand health-related materials” (p. 792); Baker followed up in 1999, stating that “unless there are major strides forward in our ability to communicate essential health information, the ‘health gap’ that currently exists in this country [America] between those with high and low educational attainment is likely to grow” (p. 316). Williams, Parker and Baker (1995) indicated that hospital admissions were greater in the population identified as being ‘low

literate' (measured by lower reading ability), regardless of any other defining characteristics. They attributed this finding to low literacy (or low health literacy, as they move from one concept to the other without pause) that resulted in reduced compliance with medical advice (including treatment protocols).

These initial reactions to NALS showed that practitioners were scrambling to understand this phenomenon (Baker, Parker, Williams, & Clark, 1998; Baker, 1999), and ideally develop interventions (Jacobson, Thomas, Morton, Offutt, Shevlin, & Ray, 1999). There was very little discussion on this topic outside this group, and certainly no publicly funded websites or initiatives. That was soon to change.

Canada began to move towards its own understanding(s) of these concepts, as is evidenced by the First Canadian Conference on Literacy and Health, held May 28-30, 2000, in Ottawa, Ontario (2001). The actual report and findings were made accessible in January 2001, and in it they introduced the idea that bringing adult learners into the situation would clarify and elucidate how literacy and health might be linked. They generated a framework for understanding 'health literacy' as it related to 'general literacy' that, while useful, largely focused on a functional level of health literacy with 'disadvantaged' persons (e.g. the elderly, Northern Aboriginals, and developmentally-handicapped individuals).

Canada had undertaken the International Adult Literacy Survey (IALS) in 1994 (sampling adults ages 16 – 90), but the final results were not made available until June 2000. Like the US, nearly 50% of the adult population sampled had a combined literacy level of 1 or 2 (Sloat & Willms, 2000). When the survey was redone in 2003, the numbers had barely shifted: 52% of Canadians aged 16 or older had a Level 3 literacy or lower, the

level considered the minimum to “function well in Canadian society” (Human Resources and Skills Development Canada, Government of Canada, 2013).

Health literacy began picking up academic and policy speed as it entered the new millennium, judging by the proliferation of publications, conferences and policies that emerged after the turn of the century (Zobel, Rowe, & Gomez-Mandic, 2003). The AMA’s, Nutbeam’s, and Kickbusch’s work from the earlier period continued to inspire and incite debate and development, branching into various domains, such as Lawrence St. Leger’s “Schools, health literacy and public health: Possibilities and challenges” (2001). In this work, St. Leger outlined the role that curriculum and teaching have in ensuring a health literate citizenry for the future: he also pointed out the challenges that adult and elderly citizens had in accessing equivalent health education. His implication for health promoting schools was that, at the very least, the teachers and parents involved with the youth would be reached with health literacy programming, thus addressing at least part of the larger problem.

Besides Nutbeam’s (2000) article, I was influenced by Ratzan (2001). Hailing from the field of health communications, he advanced the powerful idea that

Public/media relations that strive for health literacy could provide a necessary basis for informed decision-making, understanding of bias and levels of evidence, statistics and probabilities, and critical thinking skills. Effective communication strategies are not meant to manipulate and tell the public what to think, *but what to think about.* (p. 211, ital. added)

Ratzan advocated, essentially, for a citizenry that was scientifically-, medically-, biologically-, media-, and culturally-literate in matters pertaining to their health, though he

doesn't explicitly state this. I believe this approximates a critical form of health literacy. While Kickbusch (2001) also made the multi-literacy argument, she supported *adding* 'health literacy' to an existing list – quantitative literacy, scientific literacy, technological literacy, cultural literacy, media literacy, and computer literacy (p. 292) – rather than understanding health literacy as a *specific instance* of these other literacies.

Ratzan imagined that there might be a way to construct thinking for (critical) health literacy, when he proposed the following questions:

- How do I stay well?
- How can I detect disease/illness early [and treat it appropriately (self or facility based)]?
- How do I live best with illness (e.g. from an aspirin a day for those living with hypercholesterolemia to blood sugar level compliance for chronic diabetes)? (p. 212)

In the answering such questions, health beliefs emerge. For instance, "How do I stay well?" affords a wide range of possible responses, from the culturally authorised (e.g. Four Food Groups, annual check-ups, 30 minutes of activity a day) to the more individualised, and arguably less-sanctioned, strategy of minimising stress by holding weekly Friday Night Pot Parties.

Ratzan's most intriguing point (and one not made in other research either before or since), was stated succinctly following his three questions (above): "If people successfully reach the mature/aging years, they will be more prepared for the self care and generational transference of health literacy" (p. 212). There are perhaps two ways to react to this point. The first is with respect to the *current* 'elderly' population. The large number of seniors

identified as ‘not health literate’ (88% of Canadians over 65, according to the Public Health Agency of Canada (2011)) are the product of an earlier era, and it’s unlikely that heroic efforts towards contemporary health literacy will have much generational effect. The second is to question the feasibility of such a future: one where the speed at which technology, medicine and ‘best practice’ policy changes will have the effect of leaving those less involved in the mainstream culture disenfranchised. If this latter point is the case, then Ratzan’s idea of an aging population capable of the ‘transference of health literacy’ is largely unattainable, because the constant flux of health theory and practice will always leave the outliers (at a minimum) at risk of being left behind.

Ratzan’s argument also highlighted an important consideration for this study, where I am explicitly examining both how the researcher has encountered health literacy as a patient and parent, and how such ‘health literacy’ is/might be generationally transferred to my children. This requires consideration both from the educational (curriculum, teaching, learning) standpoint, the long-term/chronic patient’s “interrupted biography”, and from the maternal theory/practice stance, all of which we will return to in the coming pages.

At around this point in time, the increase in writing begins to look at the measurement of health literacy, and the perceived need to measure outcomes and value-for-investment (Nutbeam & Kickbusch, 2000). In addition to the TOFHLA and the TOFHLA-S (Test of Functional Health Literacy in Adults, English and Spanish) in the late 1990s, the REALM (Rapid Estimate of Adult Literacy in Medicine emerged in 2003 (Bass III, Wilson, & Griffith, 2003), and the NVS (Newest Vital Sign) screening tool was launched in late 2005 (Weiss, et al., 2005). In the intervening years, the number and type of assessments for ‘health literacy’ has only broadened, taking in a wider and wider scope of

‘health’ areas, i.e. dental health (REALD – Rapid Estimate of Adult Literacy in Dentistry), diabetes management (LAD – Literacy Assessment for Diabetes), nutrition (NLS – Nutritional Literacy Scale), those in need of help reading health or medical materials (SILS – Single Item Literacy Screener) (University of North Carolina - Chapel Hill, 2011), infant health information (PHLAT – Parental Health Literacy Activities Test) (Kumar, et al., 2010), the development of S-TOFHLA’s in German, Italian and French for Swiss citizens (Connor, Mantwill, & Schulz, 2013) and the more ‘holistic’ Health Literacy Questionnaire (HLQ) (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013) .

Moving into the first years of the millennium, Conlin & Schumann (2002) looked at functional (clinical) health literacy in open heart surgery patients; Schillinger, et al. (2002) investigated the association of health literacy with diabetic outcomes; Boswell, et al. (2002) launched an interdisciplinary collaboration for measuring health literacy in a single hospital’s diverse populations.

It was not just those working in health promotion/education and clinical practice that were noticing something different: Those working within the fields of ‘health’ and ‘literacy’ (as opposed to ‘health literacy’) were beginning to see that there was something, in practice, that might be understood to be ‘health literacy’. Citing evidence in the results of morbidity and mortality related to childcare, as well as in the challenges inherent in working with cultural ideas of medicine and health, Watters (2003), studying Nepal, wrote:

Not only is it difficult to adapt Western health practices and education into the larger Nepali culture, it is an even greater challenge to adapt Nepali culture and language materials to reach half the population of Nepal who do not speak Nepali

as their FL [first language] or identify and accept the majority culture as their own.
(p. 49)

In Nepal, Watters found that the literacy level of the primary caregiver had the most direct effect on the health status of the cared-for. For instance, children with an illiterate caregiver had a 75% greater chance of contracting diarrhoea than those with a literate caregiver. There was something even more important in her article though, and it is contained within this line:

The ability to enhance health through interpretation, understanding of health information, and acting on this information broadly defines health literacy...This type of program compared to curative programs can be more effective. Although the initial costs of a 24-month maternal nutrition and literacy program were greater than vitamin A distribution, the former program reduced the risk of mortality for children by half and directly reduced risk factors that predict xerophthalmia and body fat wasting (Pant et al, 1996, as cited in Watters, 2003, p. 49).

Key here was the notion that, by *empowering care providers through health education*, they became 'health literate', and the subsequent effect on those they care for was enormous.

Griffin, McKenna & Tooth (2003) noted that, amongst Australian occupational therapists, 74% used client education often or most of the time, making it the most-used treatment modality (p. 170). Further, written materials "are the most common instructional tools used by health professionals". Wilson et al. (2003), in their study of patient education materials, found that over half of the patients were not able to decipher the written materials they were given related to anticoagulation therapy and food-drug interactions

with vitamin K (p. 280-81). This reliance upon literacy *specific to health matters* is what the field of health literacy is driving at – not necessarily literacy as a technical matter, but ‘literacy’ in the broader sense.

The Institute of Medicine, in their April 2004 “Health literacy: A prescription to end confusion” (Institute of Medicine (IOM), 2004) attempted to walk the line between medicalising and humanising in their Report Brief, when they said

Even people with strong literacy skills may have trouble obtaining, understanding, and using complex health information: a surgeon may have trouble helping a family member with a Medicare form; a science teacher may not understand information sent by a doctor about a brain function test; and an accountant may not know when to get a mammogram. Health literacy could help end this confusion. (p. 1)

This passage is especially interesting, given its attempt to link ‘educated people’ with health illiteracy (and the repeated use of ‘may’ as a way to soften the statements). I have never been particularly certain how ‘health literacy’ could end the confusion of reading a brain function test, no matter your educational background, however. What I do recognise, however, is Harris’ idea of “informed understanding”, or the advocacy of a sort of health knowledge (kind of like a car’s “owner’s manual”) that, once in possession of, would alleviate the sorts of problems hinted at in the IOM’s words.

Throughout 2004 and 2005, publications continued (in the clinical realm) to focus upon the confirmation of ‘low health literacy/numeracy’ (including prevalence) with poor patient outcomes, as well as initial attempts to develop interventions and understand motivators (Barrigan, Hicks, Williams, Franco-Paredes, Duffus, & Rio, 2005; Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005; Paasche-Orlow, Parker, Gazmararian,

Nielsen-Bohlman, & Rudd, 2005; Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005; Rothman, et al., 2004).

The Canadian public health ‘scene’ was still very much determinants-focused, and writing around ‘health literacy’ was still very nascent. Two pieces came out in 2004/2005, neither of which contributed anything new to the local or global conversations (Rootman & Ronson, 2003, 2005). Also, at this time, a broader range of disciplines began publishing on the topic of health literacy: adult education (Golbeck, Ahlers-Schmidt, & Paschal, 2005), community health (Mika, Kelly, Price, Franquiz, & Villarreal, 2005), family practice (Safeer & Keenan, 2005) and nutrition (Koelen & Lindström, 2005).

Moving into 2006, it is possible to see the field expanding. Those who had been working with health literacy since its inception began to consider how to further the concept, its funding, intervention, and so forth (Kripalani, Paasche-Orlow, Parker, & Saha, 2006). More specific populations were brought into the discussion, including concerns and interventions for their (perceived) specific health literacy needs, such as cancer patients (Manning & Dickens, 2006), low-income mothers (Porr, Drummond, & Richter, 2006), critical care patients (Riley, Cloonan, & Norton, 2006), individuals with mental health issues (Jorm, Barney, Christensen, Hight, Kelly, & Kitchener, 2006), aboriginal populations (in Canada) (Antone & Imai, 2006), and the elderly (Howard, Sentell, & Gazmararian, 2006; Sudore, et al., 2006).

Additionally, the channels of communication began to be evaluated, including interpersonal communication and compliance (Cuban, 2006; Duggan, 2006) and the Internet (Norman & Skinner, 2006), with increasing emphasis being placed upon what amounted to Nutbeam’s ‘interactive’ or ‘communicative’ health literacy (and a certain

amount of ‘critical’ health literacy, but only insofar as evaluating the credibility of websites was concerned). Kickbusch continued her work in Europe, helping produce the *Navigating Health* book for the European Men’s Health Forum (with unrestricted educational grants from Pfizer, Inc., and the EU government) (Kickbusch, Wait, & Maag, 2006).

In Canada, Rootman wrote as well, now challenging Canadian doctors to become a presence in the global discussions on health literacy in “Health literacy: Where are the Canadian doctors?” (2006), while the Canadian Public Health Association finally produced a document outlining potential health literacy interventions, drawing extremely heavily upon the extant research, writing and theorising coming from the United States (Canadian Public Health Association, 2006).

Health literacy continued both its disciplinary and its global spread through 2007 (Tang, Pang, Chan, Yeung, & Yeung, 2007). The proper place and time to ‘start’ health literacy education became a topic of discussion (Brown, Teufel, & Birch, 2007; Logan, 2007), with educators proposing various health literacy curriculum models for youth. Logan’s paper was especially interesting, in that in its surveying of prevailing attitudes towards different instances of health literacy (in his words, “clinical, classroom or personal education” (p. 127)), it highlighted the potential for resource disputes and professional disagreement.

Increasingly, governmental organisations in the U.S. designed dedicated digital space for health literacy discussions, such as the Agency for Healthcare Research and Quality (AHRQ) (2007), the National Institutes of Health (2007), the North Carolina Institute of Medicine (2007) and the U.S. Department of Health and Human Services (2007). In Canada, however, there was still limited discussion, with the only major

contribution coming in the form of the Canadian Council of Learning's *Health literacy in Canada: Initial results from the International Adult Literacy Survey* (c. 2004) (Murray, Kirsch, Yamamoto, & Grenier, 2007), and it further confirmed the distribution of literacy levels in the Canadian population, especially amongst the elderly.

However, in 2008 the Canadian Council on Learning launched its publication *Health Literacy in Canada: A Healthy Understanding* (2008), and more significantly, Rootman and Gordon-El-Bihbety published (through the Canadian Public Health Association) *A Vision for a Health Literate Canada* (2007), the first cohesive, Canadian-researched statement on health literacy. While it didn't particularly differ from work produced elsewhere, it did signify a commitment from the Canadian community in matters pertaining to health literacy.

As well, Don Nutbeam revisited the Ottawa Charter ("What would the Ottawa Charter look like if it were written today", 2008b), reflecting upon the impact and evolution of this charter and seminal conference event for health practitioners of various stripes, and for the emergence of a new disciplinary field. Nutbeam also picked up his health literacy analysis in 2008 with "The evolving concept of health literacy", making it clear that he linked 'health literacy' with 'health education' – one is merely the outcome of the other. He challenged "health educators to communicate in ways that draw upon personal experience, invite interactions, participation and critical analysis" (2008a, p. 2075), in order to reach both high- and low- literacy level individuals.

Pleasant & Kuruvilla (2008) identified the dual tracks of clinical and public health literacy. Coming from health communication, Pleasant brought forward issues around the various social marketing methods and metrics used to frame and educate the public about

matters pertaining to health literacy. There are a few similarities with Logan's (2007) paper, but there appears to be no connection between the two researchers.

In 2009, paediatrics and health literacy (Cheng, Dreyer, & Jenkins, 2009; DeWalt & Hink, 2009) papers started to be published, and it is interesting to note that many of the authors had already published in prior years in journals such as the *Journal of General Internal Medicine*, with no focus on health literacy and children. The other major development in 2009 was the emergence of a literature that attempted to examine the patient's perspective in the health literacy encounter (Freedman et al., 2009; Peerson & Saunders, 2009; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009) (instead of the more traditional top-down practitioner focus), something that continued to pick up speed in the following years. In 2009, von Wagner, Steptoe, Wolf & Wardle outlined a framework for health literacy based upon the health *actions* that someone takes (the evidence of the literacy). Noting that individual and external influences fed into "health literacy", and that psychological determinants, such as motivational phases, system factors and volitional control, combined with 'health literacy', they envisioned the outcomes (or Actions) as "access and use of health care", "patient-provider interaction" and "management of health and illness" (Figure 1, p. 863).

Until this point, all of the examples and citations that I have set out feature someone in a position of power and influence talking about someone else (who generally does not share equally or at all in the power and influence). The discussion around what health literacy means from the individual's standpoint was almost non-existent. This is the common complaint that heralds from earlier work in anthropology (Gergen, 1989; Van Maanen, 1988) and critical pedagogy (Freire, 1970/2008; Giroux, 1995; Macedo, 2006;

McLaren, 1992/1993). There have been a few pieces that took up the patient's perspective (but not with the patient actually speaking), such as Ishikawa & Yano (2008) and Jordan, Buchbinder & Osborne (2010). In particular, the latter article produced a list of seven patient-derived "health literacy abilities":

1. Knowing when to seek health information
2. Knowing where to seek health information
3. Verbal communication
4. Assertiveness
5. Literacy
6. Retain and process information
7. Application skills (p. 40)

In other words, for these patients, 'health literacy' is something one *does*. It is something that is enacted, and the evidence on of one's 'health literacy' is in the outcome.

As the first decade of the 2000s rounded out, the tenor changed in health literacy writing. Increasingly 'Action Plans' were in vogue, such as *Ten Attributes of Health Literate Health Care Organizations* (Brach, Keller, Hernandez, Lyla, Baur, Parker, Dreyer, Schyve, Lemerise & Schillinger, 2012). Public health was once again being strongly linked to health literacy (and the positive outcomes) (Jhommon-Mahadnac, Knott, & Marshall, 2012; Sørensen, et al., 2012), and screening tools are moving away from functional health literacy foci to more broad-based (and more Nutbeam-like) understandings of health literacy, such as the Health Literacy Questionnaire (HLQ) (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013) and the All Aspects of Health Literacy Scale (AAHLS) (Chinn & McCarthy, 2013).

One final observation: in looking through the literature review (which is heavily American), I found it provocative that Pfizer Inc. (one of the first corporations to jump upon the ‘health literacy’ bandwagon, and a frequent underwriter of health literacy studies ³), cited the following on their public policy and researchers site (http://www.pfizer.com/health/literacy/public_policy_researchers/overview_of_health_literacy_and_clear_health_communication) (with respect to the US context):

Specifically the NAAL [National Assessment of Adult Literacy] found that 28% of Whites had basic or below basic health literacy skills compared to 58% of Blacks and 66% of Hispanics. Ethnic minorities as well as the economically disadvantaged, rural populations, women, elderly, and children have all been identified by the Agency for Healthcare Research and Quality as research “priority groups” in that they often experience a disproportionate burden of disease and disparities in healthcare access and quality.

If we extrapolated, by subtracting from the population, who are we left with that *doesn't* need “extra help” with respect to health literacy? Right: Middle-class (and above), urban, young adult - adult white men. A very powerful statement. And while this quote is American, it is far too easy to dismiss its relative applicability to the Canadian context out-of-hand.

Looking back to Nutbeam’s social determinants-based notion of critical health literacy, there is another way to read the above corporate/philosophical statement: If we take health literacy to mean that one needs to learn more to be more efficacious in the medical establishment/setting, precisely *how* is this population (the ‘priority groups’) going

³ *Pfizer has financed reports and unrestricted grants to a wide array of health literacy researchers and writers, including Ruth M. Parker and Ilona Kickbusch.*

to go about *becoming* more health literate when they are already disadvantaged? Or is health literacy here envisioned as something that policy-makers and professionals do *to* or *for* these individuals to increase their health literacy (ie. compliance) or account for their low health literacy (modifying programs to include “Ask me 3”, for example)? How are the systemic issues being addressed?

Pfizer’s advice to patients was exactly parallel with the notions of health literacy set forth by the American Medical Association, and are quoted here in full:

Try to stay active when you discuss your health issues, or your family’s health issues with the health care team.

3 important questions you can ask at every visit are:

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?

Asking questions can help you to understand what you need to do, and can help to prevent medical errors. Other important questions you can ask include:

- What is the test for?
- How many times have you done this procedure?
- When will I get the results?
- Why do I need this treatment?
- Are there any alternatives?
- What are the possible complications?
- Which hospital is best for my needs?
- How do you spell the name of that drug?

- What are the main side effects?
- Will this medicine interact with medicines that I'm already taking? (Pfizer Inc., 2002-2012)

Bear in mind that any benevolence ascribed to this multi-billion dollar organisation must be offset against fourth quarter (2012) statements about the decrease (by 9%) in revenue due the loss of exclusivity on patents for such frequently prescribed drugs as Lipitor and Geodon (Pfizer Inc., 2013). Beyond this, it is unlikely that Pfizer supplemented physician income for the time required to address this extensive list of questions.

In 2013, the National Institutes of Health (US) carried the following on its website <http://www.nih.gov/clearcommunication/healthliteracy.htm>. After a promising start with “The concept of health literacy extends to the materials, environments, and challenges, specifically associated with disease prevention and health promotion”, it goes on to say

...an individual is considered to be “health literate” when he or she possesses the skills to understand information and services and use them to make appropriate decisions about health. Areas commonly associated with health literacy include:

- Patient-physician communication
- Drug labelling
- Medical instructions and medical compliance
- Health information publications and other resources
- Informed consent
- Responding to medical and insurance forms
- Giving patient history
- Public health training

- Assessment for allied professional programs, such as social work and speech-language pathology

It appeared that the National Institutes of Health (of the U.S. Department of Health and Human Services), and multi-billion dollar private corporation Pfizer were on the same page. This may have been coincidental (as in ‘health literacy’ really and truly comes down to these ideas), or it may be a meeting of like minds, in a far different sense.

Regardless of the debates, health literacy seems to have placed itself squarely in the crosshairs of developed countries governmental and professional policy makers, including the Public Health Agency of Canada (2011), the Canadian Council on Learning (2008), the Canadian Medical Association (2013), the Institute of Medicine Academy of Sciences (Institute of Medicine of the National Academies, 2013), the National Institutes of Health (National Institutes of Health, US Department of Health & Human Services, 2012), the UK’s Health Literacy Group (2011), and the Australian Bureau of Statistics (Kondilis, 2008), among many others. Pleasant undertook a global assessment of health literacy, publishing his findings in 2012, which showcased the extreme diversity in terms of health literacy research, philosophy and resources in dozens of countries.

Two things should be apparent from the preceding review of the literature on health literacy: the first is that the past fifteen years have seen an exponential increase in both the number of publications in the discipline and the range of fields embarking upon health literacy research and discussion; the second is that, while health literacy is very obviously something that affects the individual in her or his quotidian life, that is precisely the population who has had no voice in these discussions. By focusing this work upon the

lived experiences of a single individual, there is an opportunity for in-depth exploration of the various ways in which the notion can be, and is, understood.

scene vi: The Methodological, Theoretical, Interpretive, Political, and Narrative

Earlier, I itemised the five dimensions of *bricolage*: the methodological, the theoretical, the interpretive, the political, and the narrative. The dimensions of *bricolage* are essentially the various ‘turns’ of the crystal I imagine my topic and my subjectivities to be. My purpose in this section is give brief consideration to those specific elements that constitute the fabric of this study’s *bricolage*.

I present this work as a “Five Act Dissertation”. There are certainly many resemblances to the classic five-chapter approach, and the traditional pieces are present (introduction, literature review, data set, discussion, conclusions). However, the treatment of the text within each section, narratively, varies. This choice rests on the belief that the work is best served by an approach to both thinking and writing that diverges from the conventional. Such a break with tradition functions as an interruption (Bury, 1982), an idea that is very important to the foundation of this study. Using a theatrical form, both in voice and format, positions this work as a performance (in particular, the treatment of the ‘data set’ of Act III). I was first inspired by the work of Ross E. Gray, a Canadian working at Toronto’s Sunnybrook Regional Cancer Centre (Gray, 2003). The notion of a performance interrupts the fluidity with which we often regard our experiences and our social positions: by setting up such a juxtaposition, I hope to engage my reader/listener in a questioning of those things that are frequently take for granted, or at minimum simply never thought about (and subsequently not talked about).

By ‘interrupting’ the normal process and relationships, I am attempting to create a space in which readers and researcher alike can consider their roles and reactions. I do not wholly rely on the theatrical form – that is to say, on a script that adopts performance conventions – but rather I employ it in select places, most obviously Act III. Again, this is intentional: by suspending the narrative line, and the study’s work, between various stylistic ‘voices’, the continual interplay of interrupted forms is meant to offer a new space for thinking.

There are, of course, innumerable ways in which a ‘play’ might be constructed, and an equal diversity of voices with and through which the playwright might speak. As it became evident that individual, impacted voices were never the voices of the medical professionals or policy-makers speaking on health literacy, but only heard occasionally as research subjects and anecdotal embellishments, it became equally apparent that *those* voices were, to me, the most aesthetically, philosophically, and perhaps even conceptually critical to hear. After considering a number of methodologies, and toying with how to present the voices in the text, I arrived at a place where I believed (and still believe) that an auto/ethnographic approach is best suited to the work. This meant that not only would the researcher speak, but the researcher would also be the one experiencing and commenting upon these experiences within the larger framework of social role(s). The choice was made to have one character as the (almost) exclusive ‘voice’ of the data.

But what is the nature of that voice? Certainly a case study appealed to me, as did a life story – in fact, I wrote partial drafts of both. However, I eventually succumbed to auto/ethnography when I could not reconcile the notion of ‘participant-observer’ and ‘other’ with my experiences and intent. Well aware of the criticisms levelled against

auto/ethnography and auto/ethnographers (not to mention qualitative methods as a general class of research), including lack of rigour and therapy-parading-as-research (Humphreys, 2005). I did not make the decision lightly or easily. It is possible to view my personal involvement in the study's subject matter as a dangerous, if not downright treacherous, decision; I did not even recognise my work as 'auto/ethnographic' for quite a period of time.

Nevertheless, as my literature review proceeded, I was forced to face facts: while I was pursuing other lines of research focus and methodology, my life was happening in big, bold letters. I attempted to ignore these letters. They eventually made themselves into words and, if you'll forgive me for belabouring the metaphor, those words demanded to be read. For, in fact, while I was *reading* about health literacy as envisioned by researchers, clinicians and policy-makers, I was *living* the process of becoming (or not) health literate. I was being offered the apple: my choice was whether to eat what I was freely (if painfully) being given.

I believe that there is immeasurable value in my broad array of 'health and wellness' experiences over the duration of this project, all of which have contributed to my emerging and/or enhanced health literacy. Nonetheless, the experiences I have had, and the learning I have taken from them (especially with my knowledge of the discipline of health literacy foregrounded), would have lacked a depth and sophistication that they currently possess without the fundamental addition of education. Before that sentence confuses you, let me elaborate: what I write about, however auto/ethnographically or performatively, is at heart a triangulation. The three points that influence each other are health literacy, experience, and the theories and concepts I encountered in my doctoral program (some

assigned, others discovered along the way). This is where Pinar's (2004) conceptualisation of *currere*, and its complicated conversations with the educational experiences (intentional and unintentional, conscious and unconscious), intersects with this work.

I was cautioned early in my 'program' to keep it simple: only choose one or two major theories to engage with, lest I fall down a rabbit hole (and never find my way out). Wise advice. However, in my search to uncover the connections between ideas, to develop deeper understanding(s) of health literacy, I have had to travel (at least intellectually) far and wide, and down many a rabbit hole. Impossible as it might be to trace all of the influences that have impacted my thinking, and more importantly, my process of unpacking 'health literacy', there are key ideas that can be at least acknowledged. Each of these will be detailed further in the next pages.

Coming to think of these key ideas (or theories, concepts, methodologies, take your pick) as 'actor's – not to be confused with 'characters' – has been thanks to the theorising of Arthur Frank. In his 2010 work, *Letting Stories Breathe: A Socio-Narratology*, he wrote, "the difference between characters and actors is their respective capacity for motive" (p. 31). The actors in this story allow, cause, or motivate the main character to *act*, but they do not, in and of themselves, have any capability for action of their own. In particular, the actors in this narrative are more philosophical or theoretical than is perhaps normally the case – it is not an everyday situation where critical theory drives a narrative line. However, this feature contributes a great deal to the uniqueness of this piece: it is *because* these actors were encountered in conjunction with the narrator/character and the

narrator's experiences with the realities and notions of health that "emplotment" (p. 193) occurred, and a narrative ensued.

The actors, then, include: health literacy theory and practice, auto/ethnography, maternal practice, critical theory, *currere*, reflexivity, hermeneutics, and biographical disruption/critical illness narratives. Added to this there is a large cast of 'extras' who, while not necessarily driving the narrative line, certainly contribute – you will hear their voices in and through others, but do not merit a further exploration for my purposes herein.

Maternal Theory

There are at least two reasons that maternal theory is important to this particular study. The first is the connection between maternal theory and the identity of the author (me), and the second is the relationship that maternal theory has with health literacy.

What does health literacy have to do with maternal theory? Everything, really. Consider, for a moment, who the primary purveyors of culture are. I believe the answer is principally 'mother' (in the maternal female sense), before all the marketing, the peers, the larger cultural influences. Despite parenting and equality rhetoric (and the very real notion that males/fathers *can* and *do* engage in caretaking work), the fact remains that women do the majority of caretaking in Canada (Bushnik, 2006; Milan, Keown, & Urquijo, 2011). Consider the following Canadian statistics: Dual income families, where the mother works full time, split the childcare 49.8 hours/week (mother) to 27.2 hours/week (father). If the mother works part-time, those numbers shift to 59.4 hours/week (p. 20). When the youngest child in the household is less than five years old, the average number of hours per week spent on childcare is 67.5 hours for mothers, and 30.2 hours for fathers (p. 20). If we're looking at the childcare average when the youngest child is between 5 and 14 years

old, the women commit 37.7 hours per week to childcare as compared to 19.7 hours per week for the men. In all cases, this represents a statistically significant difference (at $p < 0.05$) (Milan, Keown, & Urquijo, 2011, p. 20).

Of course, this data does not include numbers associated with childcare outside the family home: for many children, their care is in good part provided in daycares and dayhomes, by extended family and friends, and nannies. In 2002-3, the average number of hours spent in non-parental child care for children 5 and under was 29.2, and for Alberta it was slightly lower, sitting at about 23 hours per week (Bushnik, 2006, pp. 23-24). Taken together, this data indicates that it is the female in the household, most frequently the *mother* (remember, this is the specifically Canadian context), who is taking on the largest percentage of childcare, and is therefore the primary *health* educator of her children. This fact cannot be undervalued. When we take that health literacy is more accurately *cultural* health literacy, then we can extend the argument that mothers are those that are teaching the curriculum of health literacy (if there is such a thing), especially in the formative years of early childhood.

But from where do mothers get their notions of health literacy? Well, from the earlier generation of caregivers (i.e. their mothers), but there are additional sources as well, which extend from the mother in ever-widening circles: extended family, community, media/government, commerce, and culture. Personal experience also plays a critical role in how a mother defines health literacy for her children (through her maternal practice). It would be nigh impossible to catalogue and measure the myriad influences.

The second reason that maternal theory matters within the context of this study is the particular relationship that I have with the notion(s) of ‘mother’ and how such identity

constructions impact my understanding of and actions with respect to my own mothering practice and how those manifest as ‘health literacy’ (or not). When I began this process, I had no issues with what ‘mother’ meant: your mother was the female who, most commonly, gave birth to you and raised you, but could also include adoptive mothers and step-mothers. Some were good at being mothers, others were atrocious: regardless, it was a female (unless something ‘strange’ had happened in your family), and that female cared for you on some level: generally (at minimum) for your survival, and ideally, for your overall wellbeing. While I can’t say that I’ve redefined ‘mother’ for myself, I can say that my understanding and appreciation of the notion of ‘mothering’ has expanded considerably from my earlier, unreflective days – that, and I am far more conscious of my actions (and what their implications are).

Like everyone, my cultural environment shaped me. I picked up words and images from those around me. I heard the occasional comment about ‘feminists’ who hated men and who put themselves and their careers before all others. Some, so much so, that they *didn’t have children*. It was one thing to not be able to have children, it was entirely another to *choose* not to. So, while first wave feminism’s gains were ‘good’ (and believe me, in my rural town, this wasn’t always a self-evident position) – women could vote, go to school, own property – second wave feminism’s social understandings and gains were not as readily accepted (or even given lip service). This was how the world was framed.

My father glorified my mother, because she was a stalwart stay at home mother: the noblest human being conceivable. My paternal grandmother also stayed at home with the children, until later on, when she helped my grandfather run his mechanic shop (and provided him with hot meals each lunch hour – another very honourable calling), and my

maternal grandmother worked as a janitor, because poverty (and number of children, and ‘bad habits’, like cigarettes, alcohol and gambling) required a second income. This grandmother was a ‘bad’ mother, at least in the historic telling: she didn’t stay home with her children, she didn’t particularly care for their wellbeing, and she put her own needs and desires before her family’s. My mother strove to be the diametric to her mother, in all possible ways.

Many of my friends had ‘bad’ mothers, too: ones who worked, ones who’d rather be visiting or shopping than parenting, ones that didn’t volunteer at the school, ones that were single mothers (all divorcées, another problematic social role), and ones that didn’t take care of their children properly – they fed them sugar, didn’t take them to the doctor, didn’t teach them personal hygiene or manners. This is most certainly a reading of the role of ‘mother’ based on what I was taught, implicitly and explicitly, by my world. And when family finances necessitated my mother’s return to work (as a helper to my father in his business), she maintained the aura of motherliness, despite the fact that keeping up the previous standards of homemaking and mothering were no doubt crippling.

This reflection provides, I hope, a sense of the uncontested notions I held of what mothers were and what mothers did and, almost by default, how I defined for myself the role of mother (which, in turn, worked as a behavioural script for me later in my life). Had I been pressed to reflect upon the notion sooner, perhaps I would have realised how simplistic my ideas were. Perhaps.

Exposure to varied literature and perspectives during the formative years of this study undoubtedly influenced my evolving notions of mothering and how mothering was (and is) linked to health literacy. In particular, the history and theory of feminism over the

past 150 or so years seemed to push me. I found Lisa Maria Hogeland's (1998) observation acutely accurate: "[F]eminism can be understood as a form of literacy, a set of 'reading and interpretive strategies that people who identified themselves as feminists applied to texts and to the world around them'" (p. 4, as cited in Kline, 2005, p. 89). As part of my doctoral coursework, I was exposed to critical theory, and its origin in Marxism, which led me to feminism. Realising that this might be a useful framework with which to re-regard my world, I began, ever so slowly, to become 'literate' in this fashion.

From feminism, I happened upon the references to Rich (1976/1986). It wasn't long before I realised that a whole 'mother-as-theory-and-practice' discipline rose up around her initial work, and that it was not a simple set of concepts to grasp. By declaring that 'motherhood' was a culturally circumscribed, paternal (sexually hierarchical), hegemonic role downloaded to women who bore children, while 'mothering' was the *act* of caring for another, primarily young, human, she opened Pandora's Box for many. I, of course, didn't come to her work until much later – by temporal definition, I fall within the domain of 'third-wave' feminism, a sort of hyphenated post-modern feminism that attempts to recognise the situatedness of all females beyond the simple fact of XX chromosomes. While I fully recognise that these are valuable areas of thought and study, my primary concern is with the notion(s) around mothering, and I will limit my comments to this area.

I struggled with the question, "What do I/we mean when we say 'mother'?" Do we mean the *role* of mother, the *work* of mother, the *relationship* of mother, the *biology* of mother, or the *psychology* of mother? Are females, by evolution and biology, programmed to care for young? Or is 'mother' simply culturally determined, and learned? Is there an

essential ‘mother’, in terms of what a mother does? And how does ‘mother’ differ from ‘father’? Or, for that matter, from ‘parenting’?

These, and more, have been debated in the biological (Brizendine, 2006; Taylor, 2002), feminist (DiQuinzio, 1999; O'Reilly, 2006), historical (Thurer, 1995; Walker, 2000) and maternal theory literature (Ruddick, 1989). From the reductionist and essentialist arguments of psychoanalyst Nancy Chodorow (1978), to the Marxist analysis of Walkerdine & Lucey (1989), to the cultural anthropological evaluations of Douglas & Michaels (2004), Everingham (1994), Friedan (1963), Hays (1996), Warner (2005) and Wolf (2001) (and everything in between), these questions have been batted about. The consensus is simply that there is no consensus. Does this then mean that there is no point in continuing the exploration? Certainly not.

I do often question why I do what I do as a mother (and this has been highlighted by my exploration of ‘health literacy’): obviously, my upbringing has been fundamental, but so has all that I have read and experienced during my (brief) tenure as a mother. I try to be sensitive to the cultural cues that I receive, from marketing, to expert ‘advice’, to government policy, but I am undeniably influenced to some (immeasurable) degree in ways I can’t pin down. Even researchers know very little about how mothers regard their work as mothers (Ribbens, 1994, p. 7).

It is when I watch documentaries such as *Babies* (Chabat & Balmès, 2010) that I am reminded how very culturally embedded I am. When Ponijao’s Namibian mother wipes her bottom with a dried corn cob, and then rubs it on her (the mother’s) knee, or when Bayar’s Mongolian mother swaddles her tightly and leaves her on the bed in the family’s yurt, unattended for lengthy periods, so that she (the mother) can tend to the livestock, I am

startled into questioning *why* I find such things shocking or repulsive. What is inherently wrong with using a dried corncob rather than mass-produced, energy-intensive ‘toilet paper’ to take care of business? After all, my ancestors used corncobs, among many other things. The Eaton’s catalogue was a popular choice with my father’s family, for economic reasons, when he was young (the Sears catalogue less so, as the glossy paper wasn’t as comfortable), and his father told him stories of using clumps of grass out on the prairies. Even today, there are families in my city that can’t afford the luxury of toilet paper, and use whatever is available for such hygienic necessities. I do, in all honesty, recoil a bit at the thought of wiping the corncob on my knee, but I suppose that when you are already using dried dung as a fuel source in an area that receives little rain (making water-based bathing a low priority), it becomes far more sensible.

What is wrong with swaddling your child and leaving him or her (safely) on your bed for a few hours while you garden? After all, if I had adopted that stance with my sons, I would have gotten a lot more done around the house, and in all likelihood my dissertation would have been done a long time ago. Here is the list of *why*, in my culture, you cannot do this: your child will develop psychological problems associated with abandonment; your child may sit in a dirty diaper for a long period of time, getting a rash or becoming comfortable with being dirty; your child might be crying; your child might be hungry; your child might choke to death; your child won’t get the stimulation needed for his or her development (linguistic, social, etc.); your child may roll off the bed and get hurt or smothered; if you have a dog or cat, the animal may injure the child; if your baby has siblings, the sibling may hurt (or at least torment) the child (which *does* happen, though non-fatally, in the movie *Babies*).

Does any of this make the Mongolian mother a *bad* mother? After all, the Mongolian people have survived a very long time in some of the harshest conditions in the world, and I suspect that (other than the motorcycle ride to and from the hospital depicted in the movie) not a great deal has changed in childrearing in the Steppes of Mongolia in quite some time. Now, what if that Mongolian family immigrated to Calgary? What then? What would happen if it became known that that same mother was leaving her child swaddled, and alone, for periods of time while she went to the grocery store (the contextual equivalent of caring for the livestock)? Well, for one, Child and Family Services would intervene very quickly. You are endangering your child, in our cultural milieu's lexicon. I suspect that, if it is seen as a cultural 'disconnect' between Canada and Mongolia, there will be an attempt by public health officials (such as social workers or public health nurses) to 'educate' the Mongolian mother in Canada's version of *culturally appropriate parenting*. If successful, this mother will no longer leave her child unattended in such a manner, and therefore she will be 'health literate' insofar as the safety of her child is concerned. If *unsuccessful*, the child faces the possibility of becoming a ward of the state. The mother is *not* health literate in terms of child safety, or at least *non-compliant*, and at some point the perceived risk to the child's survival and well-being becomes a matter of societal concern.

This is all a grand exercise in 'what if', I realise. However, it is also useful exercise in examining how 'mother' and 'mothering' are not only culturally circumscribed, but policed by cultural authorities operating under the auspices of 'health'. I do not intend to glorify any one model or culture over another: I only point to these variances as a means to

further explore what ‘health literacy’ can and might mean. These are themes we will return to in Act III, but for now they underpin the discussions about maternal theory and practice.

While I acknowledge that much has been said about motherhood and mothering in the past 40 years (in most sectors of society), it is the work of Sara Ruddick that I will draw upon in the remainder of this study. Ruddick was the first person to embark upon the close examination of mothering as a theoretical and philosophical practice (1989, though she was writing on the topic as early as 1984). She gave it the name ‘Maternal Thinking’ (and it often gets used interchangeably with ‘maternal theory’ and ‘maternal practice’), and like Rich before her, her words caused a whole field of study to spring up in their wake. In Ruddick’s estimation, the knowledge and practice(s) (“disciplined responses”) of mothering were of esteem, and as a valued social practice, it (mothering) should be accorded the same level of societal privilege and validity those deemed ‘in practice’ received, in that “maternal practice, like other practices (such as scientific practices), has its own form of thinking and vocabulary, and its own aims and goals, and both knowledge and agency are presupposed in such a practice” (Holstine Vander Valk, 2010, p. 723). Further, while the word ‘maternal’ often signifies the feminine, it does not preclude the masculine within Ruddick’s framework.

The premise was (and is) deceptively simple: those engaged in maternal thinking are fundamentally aimed at the same set of outcomes – preservation, nurturance, and training – all for the child’s fullest development as an individual. Within each of these three areas, skills and attitudes are required to generate the outcomes. Health literacy can also be understood as understanding and action directed towards preservation, nurturance, and

training, and it is for this reason that I am framing my understanding of mothering within Ruddick's model.

Preservation was precisely as it sounds: the preservation of the life of the child. Ruddick held that both the individual child, and the social group into which this child was born (and which the child will carry forward), required that the child's life be preserved. The specific means by which this is accomplished, as well as by whom, was fluid from culture to culture and era to era, but ultimately the preservation of the child must occur in the face of uncontrollable nature and circumstance, with both humility and cheerfulness. This was not simply a physical task: the child's mental, emotional, and spiritual life must also be preserved. It is readily apparent that matters of health were fundamental to the goal of preservation, and how each cultural group achieved said preservation spoke to their specific 'health literacy' or 'know how' for preservation.

Nurturance (or *fostering growth*) was the second goal of maternal practice (and, as such, had a body of maternal thinking). Beyond the preservation of the child, the maternal practice served to help the child grow in myriad ways. This required a delicate balance of gathering close and freeing the child (and the maternal self). Skills required included an ability to accept the complexity, the multiplicity, and the ambiguity of helping another achieve selfhood. Similarly, health literate thinking in the maternal called upon the ability to balance diverse health and wellness needs with those resources available for the pursuit of growth (which required a modicum of health and wellness), while still accepting uncertainty in the outcome.

Last, Ruddick identified *training*: This practice moulded the child into an individual that could survive and thrive in the larger social context into which they had been born, and

while this is obviously a fluid notion contingent upon time and place, the maternal must balance competing interests of power and genuineness in achieving this for a child. To me, it is in the *training* that critical theory and critical literacy has the most to offer conceptually: in clearly identifying my maternal praxis (my maternal practice met by and reflected back through my experiences with theory) I am attempting to avoid preparing “the invaders of the future” (Freire, 1970/2008, p. 154) as part of my *training*. Perhaps such a consciousness will make such a hope more possible than not. At the very least, I am taking these notions into my exploration(s) of the meaning of health literacy as it applies to health literacy and mothering.

Interrupted Identity

In addition to appreciating how ‘mothering’ is connected to health literacy for the purpose of this study, it is also important to explore illness identity – this is a key aspect of how I (the author) have experienced and framed this investigation into the meaning(s) of health literacy. The idea of “interrupted identity” or “biographical disruption” has proven the most useful for this purpose. Ultimately, biographical disruption does not have the effect of a pebble being dropped into a pond; rather, it is more akin to re-routing a whole waterway.

The concept of an interruption of identity caused by illness can be traced back to Michael Bury’s (1982) article on biographical disruption. It has become, in Felde’s (2011) words “a leading framework for the studies of the experience of chronic illness” (p. 101). Kleinman (1988), speaking as an observer of illness and chronicler of illness narratives, commented that “nothing so concentrates experience and clarifies the central conditions of

living as serious illness...illness narratives edify us about how life problems are created, controlled, made meaningful” (p. xiii). I can certainly attest to the truth of that statement.

Bury, in his original 1982 thesis, identified three ‘aspects of disruption’ (p. 169) that emerged out of biographical disruption: the first “involves attention to bodily states not usually brought into consciousness and decisions about seeking help” (p. 169); the second includes a “fundamental re-thinking of the person’s biography and self-concept” (p. 169); the third holds the “response to disruption involving the mobilisation of resources” (pp. 169-170) in the face of the new life that is emerging. While Bury’s concept *can* be used for acute events, what is key to understanding his work is that he is taking up the idea from the viewpoint of *chronic* illness, or an extended temporal framework (Bury, 1991). In other words, once the person has crossed over into this new life, there is no going back. Frank (2000) suggested, “Wholeness comes to mean the on-going communication between simultaneous differences. The ethical challenge is to live in the space of that tension” (p. 22). Frank (1991, 1995) has worked extensively with the idea of interrupted identity/biographical disruptions as a result of illness, and has contributed a great deal to my understanding of the idea. He has also developed approaches and theories about the process (and purpose) of narrative within the interrupted identity, something I will address further in ‘Narrative’.

As will become clear in the coming pages, I have experienced multiple ‘biographical disruptions’ that have helped form (and continue to form) my ‘illness identity’. I am responding to these events with an ‘illness narrative’ (Kleinman, 1988). Exploring health literacy (in its various forms) through such identities and narratives has the potential to offer a depth to the analysis of ‘health literacy’ as part of a *currere*. Such a

reading of a life course can potentially illuminate previously unseen perspectives. Radley & Billig suggest that what I choose to say in my narrative reflects not only my thoughts, but “also the way that society constructs these issues” (1996, p. 223). In other words, my illness narrative or my encounters with the forms of health literacy that emerge as a result of my biographical disruption(s) are auto/ethnographic.

Auto/Ethnography

Already I have bandied about the terms ‘autoethnography’ and ‘autoethnographic’ at will, without much clarification, so I will now rectify the situation. Deborah Reed-Danahay (1997) is perhaps the most readily associated with the term, but there are clear indications in the field of ethnography that questions of the self and the researcher/researcher relationship were coming into question (Behar, 1995; Bochner & Ellis, 1996; Clifford, 1986; Ellis, 1993; Jackson, 1989; Rosenwald & Ochberg, 1992; Tierney, 1999; Van Maanen, 1988)⁵ before her defining work. The groundswell, likely attributable to questions of representation and authority that define the postmodern moment, led to a distinct body of work that identified itself as auto/ethnographic (Bochner, 2001; Gergen & Gergen, 2002; Reed-Danahay, 2002; Richardson, 2003).

The key distinctions, for me, between the ethnographic and the auto/ethnographic, lie in *agency* and *perspective*. While both share the dedication of “time and energy to the setting over a long period of time, in order to richly and deeply inform...inquiry” (Kinash, n.d., p. 3), it is in the *auto/ethnographic* that the researcher steps within the circle of the researched. No longer limited to participant-observer status, the researcher takes up the object of study from the particular situated perspective of *someone living within*. It is at

⁵ In 1972, Nash et al. identified the move to ‘self-awareness’ in ethnographic writing as the next direction for anthropology. Suffice it to say, they were ahead of their time.

this point that the researcher can no longer claim no influence over the situations' developments and outcomes: rather the opposite. It is through the interaction *between* the subject of study and the researcher-in-situ that the effects of agency are both witnessed and felt. This leads to a reflexivity that is, by definition, change-making. The researcher is changed by the researched over and over again, and it is this spiralling relationship that the auto/ethnographer attempts to capture.

Engaging in an auto/ethnographic account positions the researcher's voice as primary; in reflecting the social and the individual towards each other, a complex space for discussion opens up. It is a reality where "society constitutes and inhabits the very core of whatever passes for personhood: each is interpenetrated by its other" (Sampson, 1989, p. 4). Within this particular study, the researcher's ('my') voice permeates the text, no matter the particular literary conventions I am employing in any given moment. Occasionally I reflect back observations that seem more akin to those that an ethnographer might undertake (most notably when I write in the third-person, or when I remove the first-person in a more academic-style passage that appears 'voiceless'). However, they are all undertaken, no matter the narrative aesthetic, from the perspective of the researcher/researched, and every step in the writing process (including the re-reading and revising) has altered my emerging understanding(s), and therefore the *agency* I have shown (Bandura, 2001).

Ellis, Adams & Bochner (2010) provide the single best description of my purpose and process, and it is worth quoting fully:

When researchers write *autoethnographies*, they seek to produce aesthetic and evocative thick descriptions of personal and interpersonal experience. They

accomplish this by first discerning patterns of cultural experience evidenced by field notes, interviews, and/or artifacts, and then describing these patterns using facets of storytelling (e.g., character and plot development), showing and telling, and alterations of authorial voice. Thus, the autoethnographer not only tries to make personal experience meaningful and cultural experience engaging, but also, by producing accessible texts, she or he may be able to reach wider and more diverse mass audiences that traditional research usually disregards, a move that can make personal and social change possible for more people. (para. 14, ital. in orig.)

What I am producing in these pages is a *layered account* (para. 20): I am combining personal accounts, changes in narrative voice and structure, evocative narrative, analysis, textual analysis, scholarly literature, reflection, and reflexivity to invite others into my experiences exploring the meaning(s) of health literacy within my emerging identities of mother and patient. The validity, and therefore the legitimacy, of my work hinges upon the notion of *verisimilitude*: that is, given the available information, do you recognise my words as possible and probable, believable and resonant (Ellis, Adams, & Bochner, 2010; Richardson, 2000a, b; Spry, 2001)? Does my work open up alternative perspectives that invites a conversation (complicated, in all likelihood), a “reflexive dialogue” (Humphreys, 2005, p. 852) upon the notions of health literacy?

Further, through this auto/ethnographic account, is something learned about the larger social constructs and realities that frame ‘health literacy’, within which my experiences are nested? This is, to my mind, the greatest asset of an auto/ethnographic account – the ability to place these realities side by side and, in doing so, perhaps learn something more. My theory is that my situatedness in this particular Western postmodern

middle class patient/mothering context can inform a deeper understanding of the possibility(ies) (or impossibilities) of health literacy, and what the concept ultimately can and does mean.

Critical Theory

Critical theory and its hermeneutic effect upon my life, as I've indicated early on, was something I hadn't anticipated: it has woven its way into my interactions with the world in ways that I would never have expected, as will be apparent when we arrive at Act III. Originally, I had thought of 'critical' in the sense of 'criticism', and while there is some degree of relation between the two, they are not synonymous (Dant, 2004). There are many working definitions of critical theory, most revolving around political and economic ideologies and our subservience to them (Freire, 1970/2008; Freire & Macedo, 1987; Giroux, 1995; McLaren & Giarelli, 1995) or, as framed in the positive by MacDonald, critical theory is interested in "*praxis*...[as a] theory which is self-reflective and with an interest in practices to release persons...into emancipation" (1982, p. 57). In other words, awareness leads to change (positive change, in the lexicon of critical theory).

Leonardo (2004) conceived of critical theory as a means of liberating us from the "confines" of our "common sense" (p. 11). I take this to mean that critical theory, when fully embraced, has the potential to 'remove the blinders' – it asks us to question what we take for granted, probing where we come by certain ideas and beliefs, why we choose certain courses of action over others, why we value what we do. Common sense, in Leonardo's idiolect, is rather more about *not* using one's sense.

Dant (2004) highlighted the notion that, while critical theory *does* criticise whole social formations, it does not do so with a political agenda. It strives to be as ideology-free

as possible – it is both interested in the social and the political at the same time as it recognises the insufficiencies of both to bring about change – and instead tries to dig out the “roots” (p. 2) of “perspectives and actions in the social formation”.

As Greene (1997) noted, the move towards a critical theoretical stance is disturbing: I have found that there is an actual disruption of identity that can occur. Such a deep inquiry into one’s assumptions about self and society cannot help but electrify and destabilise. Kristeva (1991) calls this ‘making ourselves alien to ourselves’ (cited in Dunlop, 1999, p. 64), and theorises that it is a condition of making ourselves receptive to difference: I would argue that it also gives us an alternative view of ourselves with which to regard the world. Given the Western context of this study, there are a number of ideological presuppositions and markers I have had to reflect upon, and continue to do so, including gender roles, socioeconomic position, biomedicine, capitalism and power structures, media influence and marketing. It might be easy to capture them all under the heading of Western Culture, but even that escapes quickly into the anathema Leonardo warns of. Critical theory might be many things, but ‘easy’ is not one of them: every surface you scrape away reveals more depth and detail than you can imagine.

I take Lankshear & McLaren’s (1993) caution dead seriously:

We argue that we are all subject to ideological inscriptives and multiple organized discourses of desire, and to a certain extent we are structured as social agents through a type of discursive ventriloquism. (p. 48)

Striving to step out from underneath such an existence, this study employs a number of analytical strategies to open up a larger discursive structure, one that doesn’t automatically regurgitate the prevalent notions about health and health literacy experiences – you may

find yourself offended, embarrassed, uncomfortable, enraged or amused. I think that Maxine Greene provided me the most intriguing conceptualisation of a ‘critical theoretical mindset’ with her words, “There is, however, the possibility of refusing the pull to the center and of revivifying the critical questions that are so tonic and so disturbing and that (many of us believe) define liberal education” (1997, p. 28). This is what I try to do in the hermeneutic dialogue I attempt to create between the scenes of Act III, and the response to/analysis of these same scenes in Act IV.

Hermeneutics

“Given that hermeneutics denotes the study of understanding interpretation and meaning one might expect that the field of hermeneutics itself would be better understood” starts the second paragraph in Deborah Kerdeman’s article on hermeneutics and education (1998, p. 241). This sentence still makes me laugh every time. Given the diversity of writing on the topic, it is easy to see where she gets this idea.

Hermeneutics has been at the centre of this work from its inception. After much reading (and struggling, as Kerdeman intuits above) I’ve decided that it comes down to a very simple concept: hermeneutics is the name for the process of push-and-pull that occurs between a person and a ‘text’. Of course, historically, this ‘text’ was literally a text. In the contemporary (and my own) usage, I believe there is room for ‘text’ to be understood as experience, multimedia ‘texts’, and even as the ‘other’.

I am grateful that I was introduced to this idea at the beginning of my research. Gadamer’s ‘horizon’ (1975/2004), that place where our consciousness is always challenged by the new and the unknown, has virtually defined my process. Throughout the development of this work, the constant shifting that has occurred, based on new texts and

that ephemeral horizon, has undeniably operated as a way to conceive of the learning (and the curriculum) that I have encountered as patient-mother-student.

Henderson (2001) gave me a working understanding that I have returned to repeatedly over the years:

Hermeneutics is practiced at the deconstructed boundaries of the sacred and the profane, the enchanted and the mundane. It is the “space” *between* the spirit and letter of some matter. As Gadamer (1975) argues, hermeneutics is practiced in the playful dialogical space between truth and method. [When] judgement is constructed through contemplating the “big picture” in the context of the specific facts of the matter, it is hermeneutic in nature. (p. 19, ital. in original)

As a conscious pursuit of interpreting these texts on health literacy, my hermeneutic intentions have coloured my life and my work. Rather than merely experiencing the events and the information that have circulated around and through me over the course (some eight years now) of this research, I have been actively engaging in the reflexivity required to deepen my understanding(s) of my own actions and reactions, as well as those of the people around me (Freeman, 2007). This situatedness has provided me with much to consider.

Throughout this study, I have encountered innumerable texts: some have been sought out, such as books, articles and websites; others have been circumstantial, such as various health facility and medical personnel encounters. Despite both the amount and the variety of the texts under consideration in this work, it has been profoundly altering to actively seek to understand the influences that continually shape and re-shape my life and my understandings, or, as I have chosen to frame it, my *currere*. In MacDonald’s (1982)

words: “To the extent that we come to know and understand more through the theory-practice relationship, we are participating in a hermeneutic process...[a] continual search for greater understanding, and for a more satisfying interpretation of what *is*” (p. 57, ital. in orig.). Far be it for me to claim that I have ‘solved’ anything or reached enlightenment: instead, every time I revisit these texts, I find something more. Every time I engage someone in a dialogue on these matters, something further is highlighted for me, and things that I had yet to consider appear before me. I imagine this will always be the case.

While many (most) envisage an ‘hermeneutic circle’, I find that an ‘hermeneutic spiral’ is perhaps more apt. Loathe to contradict an entire canon, I still must point out that, in the spirit of a circle, you return to a certain set point, and if what you are engaging in is truly hermeneutic, then you will *never* return to whence you came. Instead, the image of the spiral, with its constant movement, vertically and horizontally, captures the nature of that constant engagement with a changing individual and a changing horizon. For me, this has been true throughout this study.

Currere

During this work, I reflect upon the framework (‘method’, in his terms) that curriculum theorist William Pinar derived for the “systematic study of self-reflexivity”: *currere* (2004, p. 35). In his words, “*currere* seeks to understand the contribution academic studies makes to one’s understanding of his or her life” (p. 36), and while I believe that his intent in developing this approach was as an educator, for educators (in formal, institutionalised settings), I have found great value in his method outside of these parameters. I find that Pinar’s *currere* fulfils something of MacDonald’s (1982) vision for curriculum theory, in that it is

...less an instrument for explanation and control and more a form of hermeneutic inquiry. The dialectic with practice, rather than a validation process for theory, represent[s] two moments in the dialectic of thought and action in an enlarged and growing process of inquiry. (p. 60)

This, I understand, has the potential to broaden the interpretive inquiry upon contemporary notions of ‘health literacy’ I engage in through the experiences I capture in this work.

There are at least three ways to consider Pinar’s ‘*currere*’ or “complicated conversation with oneself” (p. 37) in my particular situation (and in direct relation to ‘health literacy’): the first is as a mother, one who has in turn been a child and a child-patient, who has been educated in the ways and means of “health” in my culture, and who now transfers this knowledge, intentionally and unintentionally, to my children; the second is as a student who is encountering the ideas of (among others) critical theory, literacy, anthropology, illness and health identity alongside the mothering and patient-duties that define my day-to-day experiences (and those ideas then reflexively bend back upon my life and inform my understandings of health literacy); and third, as an adult patient, being ‘educated’ in the various registers of acute and chronic illness and its management, and injury, who then turns around and applies this ‘learning’ to self-care, self-awareness, ‘teaching’ of professionals and lay-persons alike, all as part of the self-reflexivity of the role.

But what is this ‘method’ he outlined? He divided learning into four ‘moments’: the *regressive*, the *progressive*, the *analytic*, and the *synthetical* (pp. 36-7), and each defines a stage that the thinker goes through in order to bring about a deepened understanding of self and place as educator and individual. It is also a form of witnessing,

one that allows for the possibility of ‘complicated conversations’ with others, in the pursuit of the hope of social reconstruction (p. 37) (or, as I think of it, as change for the better of all). In attempting to bring his method to bear on my work, and despite its great utility, I have been greatly challenged. I have attempted to frame the Acts of this work, as well as the ‘play within’ of Act III, in this manner, knowing all the while that it is, ultimately, a device. Nonetheless, it has provided me with an alternate manner of considering the shape and direction of my work.

The *regressive* moment (Act III) is the stage in which I move back into my past: I free associate around notions of mothering, health and illness (as these constitute the concepts I am working with), drawing from my past those images, thoughts, memories, and experiences that “hover over the present” (p. 36). This is useful, certainly, but presents logistical challenges: every day that passes becomes ‘the past’, and everyday I step into ‘the future’. It is impossible to capture the *now*. So that leaves me with the inescapable knowledge that my target is always moving (which is evidenced in the narratives throughout this work). Certainly those memories deeply past serve well the regressive moment as data source, but it is much harder to define how those in the immediate past fit into the concept of *currere*. Moreover, for as many memories as present themselves, many more, forgotten, displaced, are not brought forward, and one must always wonder where the path would lead if those signs had been posted.

By the same token, the *progressive* moment – that which is “not yet come to pass” – is continually crossing over into the regressive moment. The deep future is feasible as a moment of consideration, yet it is impossible to discern how best to manage the continual passage of time that transitions progressive to regressive. The ‘moment’ of space is never

actually present: it is as ephemeral as the continually approaching horizon. However, it is possible to theorise how the learnings of a life might influence future thoughts and actions, and that is how the progressive is imagined in this Act.

These observations lead to the conundrum of the *analytic* moment: Pinar and Grumet envision this as addressing the question of “How is the future present in the past, the past in the future, and the present in both?” (Pinar, 1976, p. 60, as cited in Pinar, 2004, p. 37). This question positions us on a continuum, where we are continually sliding along the horizontal (or vertical, if you prefer the image), never truly stopping, but always linked to both that which is past and that which is to come. In this moment we are “distantiat[ed] from past and future functions to create a subjective space of freedom in the present” (p. 36). Inasmuch as this is possible, I have attempted to do this through the use of a narrative auto/ethnographic approach to my subject: me as new mother, me as new patient, me as a new student, all unpacking the idea(s) of health literacy.

Finally, *currere* moves into the *synthetical* moment, the moment in which I re-enter the life-I-am-living, changed by the experience of *currere-as-method*. This is the point at which the deep work I have done reintegrates into my praxis, into my life. A moment of hope, the synthetical points to a present (and future) lived as more aware, as more sensitive to the complexities of self and society. This is, of course, not entirely removed from the notions of critical theory.

The way that *currere* is envisioned is reminiscent of fieldwork (Geertz, 1988; Van Maanen, 1988): the data is gathered, analysed, and then written about (the regressive and progressive, analytic, and synthetical, respectively). The pull to make this ‘field work of the self’ available to others, through the sharing of the ‘results’ is not, I think, a matter of

self-aggrandisement or theatricality: rather, it comes from a different, much deeper place within our identities. In Geertz's words,

What it is (a task at which no one ever does more than not utterly fail) is to inscribe a present – to convey in words “what it is like” to be somewhere specific in the lifeline of the world...an authentic account by someone personally acquainted with how life proceeds in some place, at some time, among some group (1988, p. 143).

The use of *currere* as a framework for looking more closely at health literacy within my ‘life-as-lived’ is an attempt to answer ‘what it is like’ to experience (variants of) health literacy authentically, and in terms that may be recognised by others.

Reflexivity

I have never said to myself, “now, in this section, I’m going to get reflexive.” Reflexivity is an *outcome* of the experiences and learning that have framed this work. So, for instance, in conducting a critical literature review on ‘health literacy’ at the same time as reading into critical theory, and operating in my *currere* as a patient/parent, I have, of necessity, had to reflect back and through, and that process has then engendered transformation in how I regarded my world going forward. It is the hermeneutic circle/spiral, in which the “constantly renewing flow of information simultaneously revises” my perspective and my actions (Dutta & de Souza, 2008, p. 329).

Dutta & de Souza (2008) discussed ‘reflexive modernity’ as an “organizing framework for theorizing about, conducting, and evaluating health communication campaigns in the realm of development” (p. 327). I believe it is equally useful a notion for reflexive encounters with health literacy in its varieties. They then stated that, “*reflexive modernity* refers to the critical self-confrontation inherent in a modernist enterprise, and

captures the dialectical tensions between modern and postmodern elements of contemporary theorizing” (pp. 327-8, ital. in orig.). In my particular case, the dialectical tension exists on several intersecting planes, such as being a mother and being a patient, understanding the scientific enterprise and questioning its place in my life, and encountering the critical theory perspective alongside interminable negotiations of health and healthcare. This study is a discursive space, for me (and my readers) to explore these tensions.

Because this work seeks to better understand the meaning(s) of health literacy by exploring how it is manifest in various situations over a period in a lifecourse, and by its nature it a reflexive encounter of the mind with the body’s experience, there are limitations: in Butler’s words

There is a bodily referent here, a condition of me that I can point to, but that I cannot narrate precisely, even though there are no doubt stories about where my body went and what it did and did not do. The stories do not capture the body to which they refer. Even the history of this body is not fully narratable. To be a body is, in some sense, to be deprived of having a full recollection of one’s life. There is a history to my body of which I can have no recollection. (2005, p. 38)

In spite of this (true) observation, I am inclined to find value in Spry’s assessment of *how* auto/ethnography can contribute to this essential conundrum: “The autoethnographic text emerges from the researcher’s bodily standpoint as she is continually recognizing and interpreting the residue traces of culture inscribed upon her hide from interacting with others in contexts” (2001, p. 711). So, while I grant that there are limitations to reflexivity’s ability to grant me a deeper understanding and appreciation of my situation

and situatedness (and from this, the various potential meanings of ‘health literacy’), I still hold that it serves well the purpose of clarifying and distilling many notions in this study.

It would be one thing if I were to simply tell the reflective story(ies) of my experiences as mother, student, and patient: that, in and of itself, might be interesting, but it would not be considered *reflexive*. No: in order to be reflexive, it must constantly negotiate the tensions, in the hermeneutic sense, between the present moment and the horizon. It is not enough to *experience*; I must also engage with those theoretical (in this case, a constituent of my horizon) precepts my educational endeavours offer me, in relation to what I have discovered about contemporary health literacy’s place in the world. I must “not only contemplate [my] own actions, but...turn inward to contemplate *how* [I am] contemplating [my] actions” (Madison, 2006, p. 321). That is where it becomes reflexive: it is also where we cross into both *currere* and back into auto/ethnography.

If you have come away from these discussions with the sense that all of these ideas are inter-related, almost intrinsically so, you’re right: this is something I have come to understand as I have moved through this study. Each one, taken on its own, provides ample food for thought: however, each owes a debt to the others, whether it realises it or not. My aim, in part, is to weave these all together as I explore, extend, and elucidate health literacy in a life-as-lived.

Narrative

Dunlop (1999) understood narrative as a “symbolic framework in which the complexities of relationships among narrative, power, and culture are given significance and meaning” (p. 59). Further, she suggests “although we may begin with language, it is deep below the surface of language that we create new meanings for ourselves and with

others” (ibid). These two notions are pivotal in my choice of narrative prose as the literary style with which to engage with my study, and to move a step further and stage my ‘data’ (experiences). By playing with both the voice/s with which the ideas of this work are explored, and by attempting to open a space where the concepts, theories and experiences are transcended, and perhaps conceived anew in a wordless place, I am hoping to engage the reader in “creating new meanings for ourselves and with others”. I am drawn to Clandinin & Huber’s (2002) words:

...narrative understandings of knowledge and context are linked to identity. For us, identity is a storied life composition, a story to live by. Stories to live by are shaped in places and lived in places. They live in actions, in relationships, in language, including silences, in gaps and vacancies, in continuities and discontinuities...we see narrative as both phenomenon and method. (pp. 161-162)

In constructing the narrative(s) of this study, I have tried to capture those places of shaping and places of living they speak of, and through the process I have made innumerable discoveries, many, many of which have taken me entirely by surprise. There are, as will be witnessed, countless moments where I have taken unreflective action, and even in the repeated analyses in the intervening years, I have neglected to see where I have done so. The narrative structure, the layering of stories about stories, offers the opportunity to continue the ‘digging’ that is intrinsic to such an exploration.

Lock (1990) makes the suggestion that, through narrative, we can create a “fundamental language event” which creates a space for the “explanatory discourse of science and the meaningful discourse of human relations” to meet (p. 42). While I believe this to be true, I also feel that *how* such narratives are constructed impacts what this space

looks and feels like – and how, in turn, that space is understood. As such I have attempted (through the creative process) many varieties of narrative construction. What is contained in these pages represents the latest (and last, for now) evolution in the narrative ‘becoming’ that has characterised this work.

Ricoeur (1978) theorised that the plot of the narrative was built around two elements – the episodic and the configural. Episodic structure was based upon the chronology of the events being depicted, while the configuration was the overlaying of a pattern to the sequencing. In other words, while the *order* of events matters, so too does the *relationship* of the events to one another (with strict ordering being but one option). Ricoeur described it thus: “Indeed, this structure is so paradoxical that every narrative may be seen as a competition between its episodic and its configurational dimensions, between the sequence and pattern” (p. 184). This dialectic feature, inherent in narrative, is part of what makes it so powerful as a communicative choice. It is also what brings to the fore awareness of just how critical our narrative choices are to the understanding of whatever is being spoken of. It is this play between the episodic and the configural that I experiment with throughout this study: from the way that I sequence various discussions, to the manner in which I move back and forth from the personal to the public (academic).

All of the constituent parts of this study have a tradition of narrative being viewed as a powerful tool to create understanding and situate the actor within her or his realm. Ruddick’s maternal practice theorised that, particularly within the act of nurturance, narrative exchanges between mothers helped define and bolster (as well as differentiate) their practices. Frank, working with illness narratives, suggested that there are types of narratives that individuals could choose to engage in as a means to navigate their identity

disruption. In particular, the quest narrative allowed the individual a means to narratise (and therefore understand) her or his movement from ‘whole’ to ‘broken/sick’ and back to ‘whole, but fundamentally changed’. Auto/ethnographic and *currere* were/are both situated as tellings: of course, the nature is slightly different, but again, a narrative structure is a requisite if there is to be any authenticity.

It is perhaps within critical theory that the least use is made of the narrative (in terms of how writers in the original tradition spoke of their topic (i.e. Horkheimer, Adorno, Marcuse, Habermas). It is unlikely that anyone will ever categorise these writings (important though they are) as aesthetically engaging or personally reflective. Critical literacy (at least the Freirean *conscientização*) required a narrative engagement in the stories of our lives in order to reflect upon them, and to develop a critical consciousness that is the precursor to initiating change.

Given the strength of the narrative approach and tradition within my various components, it seemed almost imperative that this be the voice with which I undertook this work. Gergen observed that,

When asked for accounts of self, participants in contemporary Western culture unflinchingly agree that emotions, ideas, plans, memories and the like are all significant. Such accounts of the mind are critical to who we are, what we stand for and how we conduct ourselves in the world. (1989, p. 70)

This study, avowedly Western in orientation, centres upon the narrative conveyance of how my experiences and education have formed and re-formed who I am, what I stand for, and how I conduct myself in the world (Ochs & Capps, 1996). All of these are provided to

contextualise how ‘health literacy’ operates upon and within the individual’s (Western, middle-class) experience(s).

Finally, an acknowledgement of the presence of ‘narrative editing’ (Gubrium & Holstein, 1998) in any narrative (whether intended for reading or performing): narrative is never a ‘pure’ experience, and there is always an ‘editor’ (me) who “monitors, manages, modifies, and revises the emergent story” (p. 170). While I am cognisant of this aspect of any narrative endeavour, I am attempting to mediate this reality with the interruptions of the narrative I engage in throughout Act IV. By reflecting back upon what I wrote after a period of mental and experiential distantiation (there is a year’s gap between the final piece of Act III, and the analysis contained in Act IV), I hope to be able to engage further with the text in a manner I was unable to when I was operating as the (initial) narrative editor.

With these various methodological, theoretical, interpretive, political and narrative dimensions in hand, let us now encounter the story that frames the study.

Act Three: The Regressive

*Who wants to be confronted with the existential questions of life and death and human identity on a daily basis? And yet there are times when that is exactly what we're looking for, when we **want** to be reminded, if only a little, of what's really going on beneath the thin crust of civilization.*

(Pollan, 2013, p. 54)

The category of biography that is so conspicuous in histories of medical practitioners has not been as frequently used in the case of patients or sick people, except in some extraordinary accounts of people who suffered attacks of mental illnesses. To be the subject of biographical interest, one has to have some qualification other than being afflicted by a disease. The illness of kings, generals, presidents, saints, artists, and writers are of interest because of some other attribute of the sick person...There continue to be far more biographies or autobiographies of caregivers than those being cared for.

(Burnham, 2005, p. 35)

The difference between the concept of truth in the natural sciences and in art lies in this, that the first is true objectively, independently of the spectator, while the truth of art is completed through the reinterpretation of the spectator's or reader's own life.

(Gjengedal, Lykkeslet, Sørbo, & Sæther, 2013, p. 11)

Each person's health is a responsible performance in a social script.

(Illich, 1976/2002, p. 129)

Setting the Stage

I have spent a great deal of time trying to explain to people (only those who ask, I assure you) what my study is about. Almost invariably, the phrase ‘Health Literacy’ (never mind ‘Critical Health Literacy’) draws a monumental blank. So I am learning to rephrase it. Here is how my early attempts at conversation went:

Enquirer: *So, what’s your dissertation about?*

Researcher (Me): *Well, it’s about health literacy, and the idea of critical health literacy, as it relates to mothering and to being a patient.*

Enquirer: *(a blank look, followed by) Oh. Ok.*

Me: *(frustrated at myself) Think of it this way: When you’re sick, what do you do? Where do you go? Who do you ask? And more importantly, Why do you do it? And how do you know you’re sick? Do you do it because you think it’s ‘right’ or because you’ve been taught to (and therefore you ‘know’), or because you’ve been told to (by someone who has authority or knowledge, or at least someone you think has authority or knowledge)? How much of your own information do you gather? From where do you gather it? How do you know if it’s good information? What are your expectations of yourself and others as it relates to taking care of your health?*

Enquirer: *(vaguely recognising the relevance of the topic, brighter) Oh! Yeah, like the time my doctor wanted me to go on prescription XYZ, or therapy ABC, and I didn’t think it was necessary and I talked to my boyfriend/girlfriend/sister/mother/daughter/homeopath/Googled it/went to Chapters/watched*

Oprah/watched Dr Phil/watched Dr Oz!! And I decided to stop, and then my doctor got mad at me.

Me: *Something like that, yes. But you went through a whole process where you made decisions at every point –, other times not as much –, and every time you gathered more information (whatever the source), you had to re-evaluate your position (but not necessarily consciously). At what point did you stop?*

Enquirer: *What do you mean?*

Me: *I mean, at what point did you say ‘OK, that’s enough information, and this is the decision I’m making’, or did you find yourself caught up in the system, going ahead with things you didn’t believe in, or understand, or want, because you felt overwhelmed, or undereducated, or powerless? Were there things that didn’t make sense, or you didn’t know where to turn, who to ask? Did you ever feel you just didn’t have the words to say what you needed or wanted to say? Did you ever get talked over, or ignored? Did you struggle because you thought you understood something, only to realise, for instance, that you didn’t have the microbiology background to make complete sense of a diagnosis or a treatment? That’s just if you’re a patient.*

And what about as a mother? In our so-called ‘middle-class’ setting, you have a child, and it’s a complete information dump – and that’s before the child is born. After the child is born, it just keeps coming at you – neighbours, friends, family, television, radio, the Internet, books, billboards, posters, and on and on and on, all about your child’s health and wellness and survival and future happiness....

And if you're dealing with a sick child....!

Enquirer: *Oh my god, yes! When my family doctor sent me to Specialist 1 ½, he didn't even look at me. He was running 2 hours late, walked in, said about 3 sentences, wrote a prescription/scheduled a surgery/wrote me off, and walked out. I had a list of about 20 questions, and I'd already waited 8 months for the appointment, and you'd better bet my insurance was billed for the time. So I just try to ignore the problem. My family doc felt bad, but she can't do anything about it. And I can't even keep up with the things I'm 'supposed' to read about health for my kid....I just pray I'm doing the right things....*

Me: *Right. Of course. And what I'm doing is looking at the question both from the standpoint of a patient with a chronic condition – basically the evolution from first onset to diagnosis to living with the condition; and also from the perspective of a new mother – pregnancy, childbirth, and those first years raising your child. There's so much information out there, it's a miracle I haven't drowned in it. But then again, why should I expect to do anything but drown in it?*

Enquirer: *Ha. Yeah. I can't even find the time to get through all those little brochures they give you when you go for your vaccinations. You know, the ones with all the development milestones and whatever. Then there's that huge thing they give you when you're pregnant—*

Me: -- “From Here thru Maternity¹³”—

Enquirer: --yeah, that one, and the other one, the one for after the baby's born --

Me: -- “Growing Miracles¹⁴”—

¹³ Calgary Health Region, 2007

Enquirer: --right. I mean, what do they think I'm made of? Time? Then there's sitting in waiting rooms for well-baby checks, and calling the HealthLink line, and the learning to breast feed (and god help you if you can't or don't), and then making your own baby food or being criticised by the moms in mommy group for using jarred food, and what soap to use, and when to introduce solids and how small the damn little pieces should be, and answering to my mother, who thinks that child car seats are ridiculous and that air conditioning causes colds and that whiskey and honey rubbed on gums when they're teething is ok, and ARGH!

Me: That's my point. How do you take all the information you're constantly being exposed to, and make sense of it? Who do you listen to? Johnson & Johnson? Proctor & Gamble? Pfizer? Colgate-Palmolive? Good Housekeeping? Oprah Winfrey? The Internet? Your mother? The billboard on the way to the grocery store? The packaging at the grocery store? The mommies' group? It is so very, very complicated.

So, then, 'health literacy' is about how we come to know about things related to health, wellness, and medicine, and then what we do or don't do, and who gets a say. We're becoming some form of 'literate', but I'm questioning what the form is and means.

Enquirer: (light dawns) Oh! I get it! I totally get it!!

Me: What I want to do is shed some light on the idea from the standpoint of the patient and the mother, because it doesn't seem like anyone has – it's all about

¹⁴ Calgary Health Region, 2005

experts talking to us, and nobody seems to really want to stand up and say 'look, this is what it's like!' Wish me luck.

In this conversation, we are able to connect because of a shared world – maybe it's as mothers, or daughters, or chronically ill persons, or any other manner of a large number of possibilities. These things that we share allow us to enter into a dialogue with one another about the *idea* of health literacy (because, at its core, it is just that: *an idea*). And if we're open to the dialogue, then each of us pushes each other towards new types of understandings and perhaps even crystallisations of our own thoughts, beliefs and opinions, a sort of dialectical scaffolding. That's the very best one can hope for in such conversations.

And this is what Act Three is presented to you as: a series of conversations directly and indirectly exploring the idea of 'health literacy'. In doing so, it is also engaging *you* in a form of a conversation; yes, it is a text, but it is a text with voices that transcend the paper they are written upon. Peterson & Langellier believe that

...any mundane conversation or event can 'break through' or be transformed into performance by 'making a to-do' about it...Performance makes what would otherwise be mundane into something more: it distinguishes or frames itself from what surrounds it, it marks itself off and thereby turns back to comment on its context, and it puts this 'making something out of nothing' on display for the participants. (2007, p. 206)

It forms (depending upon your theoretical inclinations) a sort of intertextual conversation, or a dialogical moment (Lau, 2002). This narrative-performance is also an invitation. An invitation for you to consider certain aspects of your experiences that you may not have

previously reflected upon (Denzin, 2003) in the light of the notion of ‘health literacy’. And it is my hope that, in engaging in such a conversation with *this* text, you will find yourself turning to the world around you, and asking those in your life to continue the conversation with you. Perhaps that, ultimately, is what literacy is.

Health literacy ‘moments’ for the purpose of this study included the combination of scientific, media, civic awareness and “know-how” (Gadamer, 1975/2004) instances that asked me to engage the existing systems and resources related to health for my and my family’s wellbeing (which included, but weren’t necessarily limited to preventive, information, screening, and treatment acts). It extended beyond the coding/decoding that reading entails, and it went past the number manipulation that numeracy requires. In turns, I needed to have a base-level understanding, in *my cultural milieu*, of what ‘health’ meant, and it asked that I grapple regularly with what my relationship(s) with these notions *could* or *should* be.

In order to truly grasp the breadth and depth of health literacy – what it is, what it does, how it happens (or doesn’t), what challenges lie below the surface (theoretically and policy-wise), it was necessary to examine the concept *in situ*. Ethnographic in orientation, to be sure: however, more than this, the work required the *auto*/ethnographic. Health literacy has not, to my knowledge, been explored as something that *was happening to someone* as a process or a ‘becoming’. To date, it has been discussed as *happening to others*, or more precisely, *something someone (but never the author or researcher) acquired and then used* (cf. literature review, Act II). Without exception, every scholar, policy-maker and clinician that has ever written a word about health literacy was (and is) inextricably woven into their own cultural health literacy fabric: however, the fact is that

not one has written a word about his or her experiences. The disciplines and fields currently involved in the discussions on health literacy do not have a history of such forms of writing or treatment of the subject/author. This missing piece has the potential to illuminate many heretofore un-discussed, and perhaps unrealised, aspects.

The vast majority of literature on health literacy has examined the definition, measurement, socio-cultural-economic factors, implementation, reorganisation, and communications required for health literacy to be the *outcome* of health education efforts for populations, both expert and lay, as in “*education > literacy*”. The research and writing has had a distinct dualist tone: chronic/acute (infectious); developed world/developing world; minority/majority; literate/illiterate (low literate); clinical/public. None has situated explorations of the meaning(s) of ‘health literacy’ in the context of a life-as-lived, exploring the realities, challenges, contradictions, complexities and complications of the actual *enactment* of health literacy. This is what we’re going to do next.

The following timeline provides a snapshot of the quest: I have selected moments from the past that (hopefully) will take you (the reader or witness) into a different world, one that is largely defined by emerging literacies related to health and wellness. While I do spend some time in the ‘deep regressive’, the larger amount is taken starting with the pregnancy and birth of my first child, until late 2012. Through thick description (Geertz, 1973/2003), I intend to invoke, provoke, and evoke the atmosphere of the times and places past that have fed into the present attempt at making the interpretation(s) of health literacy real and meaningful, painful and funny. Alexander (2011) suggested I might be able to give you, as “the audience, an experiential instance for understanding [of] the meaningfulness of expression, and the political importance of the utterance in a larger

cultural context” (p. 100). Ultimately, what follows is partial: that being said, I hope that you feel some of the frustrations, confusions, embarrassments, humour, ridiculousness, and more, that I have, if only vicariously. Perhaps you will feel exasperated, ashamed, angry or derisive *at* or *for* me. Either works.

The scene listing:

- 1974 – 1982: The Really, Really Deep Past
- 1982 – 2004: Before
- 2004 December – 2005 September 1: Transition to ‘Now’
- 2006 April 25 – Til the End of Time, Learning to be ‘Patient’
- 2007 August – A Lesson in Mortification
- 2007 December – 2008 March: Mistaken Identity
- 2008 March, Easter Monday: The Myths of Freedom of Information, Protection of Privacy, and Informed Consent
- 2008 March: Playing the Odds, or the Home Stretch
- 2008 June – 2009 May: Mommy OT & ContraBand
- 2009 March: Pox Parties & Vaccination Wars
- 2009 October – 2009 November: To the Edge of Sanity
- 2010 February: Multi-Tasking Mommy
- 2010 February, Continued: A Trip to the Grocers
- 2011 May: The Prolapse Files
- 2011 June: Back for More
- 2011 November – 2012 March: Epiphany
- 2012 January: Coming Undone

- 2012 January: There is No ‘Worm’ in Ringworm
- 2012 February: This is the Last Time (Again)
- 2012 February: Critical Thinking for Breakfast
- 2012 March: The Embarrassing Truth
- 2012 March: Groundhog Day
- 2012 July: Don’t Wear Tight Shoes
- 2012 August: There Really is a ‘Worm’ in Hookworm
- 2012 October: And the Oscar Goes To...
- 2012 November: And So It Begins Again

A note about the text: Throughout this work, there are academic citations. There are two potential ways to handle these, from the performance’s standpoint: the first is to ignore them, and only work with the text-proper; the second is to use media, either electronic (e.g. projections) or static (e.g. placards) to convey the citations.

Now it is time to dim the lights and relax back into your chair. As the murmur of the audience around you dies down, a light comes up – a single spotlight, centre stage, with a stool and a sign:

“In the beginning is an interruption” (Frank, 1995, p. 56)

Throughout this entire work, a discrete stagehand brings props onto the stage, sometimes during a piece, sometimes before a piece, sometimes just as the piece is starting. The narrator always acknowledges this person in some small way. These props consist of books, big and small, file folders, stacks of printed articles, a laptop, an iPad, loose paper, pens, cups of coffee or tea, and so forth. And as the play continues, these items don’t go

away: they simply continue to accumulate in the various areas of the stage. The narrator-performer makes use of them when and if she chooses: maybe she thumbs through them, maybe she makes notes, maybe she uses them for a stool, maybe she drinks from cups, and so forth. The impression is of slowly becoming engulfed.

The narrator enters, taking her place in the spotlight. She takes down the previous sign, and holds up another:

scene i 1974–1982: The Really, Really Deep Past

She seats herself, and begins:

I am here to convey to you the complexities of the notion of ‘health literacy’, to try and understand what is actually *meant* when that phrase is used (and believe me, whether you know it or not, it’s being used by those making decisions about health and health care). I know: you probably just thought “Huh?” or “Wha?”, and not in the “tell me more” fashion. That’s not surprising. The playwright (not me – I’m just the ‘voice’) first thought of using a half-dozen or so of the definitions of ‘health literacy’ being used right now (and there are a lot more where those came from), and projecting them up all around me. She also thought it might be kind of cool to have a bunch of voices from different parts of society all fighting for airspace, all talking about health literacy, like doctors and nurses and politicians and academics and so on, and that probably would have worked. But I suggested to her that maybe, in order to understand this very odd, very academic-y idea, I should just tell you some stories. I personally really like stories.

So, instead of overwhelming you with a bunch of research (which, she assures me, she will do elsewhere), the idea was to bring you, the audience, in at the ground level.

Really let you see how becoming ‘health literate’ (because doesn’t ‘literacy’ lead to being ‘literate’?) in a bunch of different ways might actually *happen*.

A few things have to be acknowledged as we start: I’m one person, with one person’s perspective. That’s a limitation. I come from a certain time and a certain place, also a limitation. I’m only going to tell you my stories – both the things that have happened to me, and happened around me. I’m mostly going to focus on seven years of my life. I will talk about family, but I will say very little about my husband. He’s great, and he’s the reason I can even stand here in front of you, but he’s more like the tech director and executive producer than the star character.

First, I’d like to talk about how I became ‘me’: I was born in Lethbridge, Alberta, a small prairie city. My birth, I’ve been told, was traumatic. Probably more so for my mother than myself, but who can tell? After several hours ‘in labour’ at the hometown hospital (about 40 minutes outside of Lethbridge), my mother was rushed by ambulance to the city where her ob/gyn practised. After an examination, my parents were told that I could not be delivered ‘naturally’. Of course, this means, if you really think about it, that I could only be born ‘unnaturally’. Semantics aside, I came into the world via caesarean, and my father tells me that the first time he saw me, I was in a plastic bag. Why, I don’t know. I’ve always had this image of my dad seeing me arrive, via the elevator, being carried in a plastic bag, with my head sticking out, by some nondescript orderly.

All was well after this - more or less. Normal illnesses, normal bumps and bruises, normal (and regular) health care check-ups, except that I had bouts of respiratory ailments (bronchitis, pneumonia, bronchial pneumonia) in my early childhood, most ending in hospital stays in Lethbridge, and most often at Easter.

Some of my earliest memories, in fact, are of those stays: the oxygen tent that I was kept in, the playroom on the paediatric ward, the bathroom where the nurses did our daily baths. That room in particular has stuck with me through the years: sterile white, and in my child's memory it was huge, with head-high cabinets all the way around. These counters had hospital gowns, linens, towels, scales, diapers, and stacks of tidily displayed items. In the centre of the room stood a claw-foot, cast iron tub. I remember how cold the rim was. The nurse would take me down to the bathroom, and she would run the bathwater. She always added Johnson's Baby Shampoo (it's iconic yellow packaging unmistakable) under the warm running water, and swished it about. I remember sitting in the gathering water, looking at the little bubbles building around me. I remember being washed - quickly and efficiently - by the nurse, then swooped out and wrapped in a warm towel. Back into pyjamas, I was taken back to my room, feeling very clean, and very special indeed.

These are romantic memories. I don't remember feeling alone or abandoned or any of the other things one might nowadays expect of a hospitalised child - I was mostly very happy to be the centre of attention, and it was all quite a grand adventure (except for the needles). It wasn't until years later that I realised that, with my sister only 22 months younger than me, the majority of my hospitalisations were with her in our lives. Respiratory illnesses were not baby-friendly, so my parents were told to keep my sister away. My mother didn't drive in the city (she'd only learned to drive a few years earlier), so even if she had been comfortable with a babysitter (which she wasn't) the fact remained that my father worked during the day and couldn't drive my mother to the city during work hours. I spent most of my days, and all of my nights, alone - at least from family. For a

few brief hours in the evening I saw my parents. I'm not sure that this struck anyone as particularly abnormal. I'm sure that it wasn't the perfect situation, but I don't think it was overly dramatic, either. It was simply what you did.

First set of books is brought in and placed near the narrator.

Perhaps because of these experiences, I developed a very early fascination with all-things-medical. I discovered, on our basement's bookshelves, *The World Book Illustrated Home Medical Encyclopaedia* (World Book - Childcraft International, Inc., 1980), -- and my obsession took root. In the first few pages of Volume One (after a quick-and-dirty physiology and biochemistry lesson, complete with full-colour artist's renderings!!), there appeared an Index of Symptoms. I figured out that, to use it, you simply found the section of your body in question -- for instance, leg, hip, knee and foot -- and then you identified your symptom, like 'ankle, painful' or 'foot, itching'. Under this heading, you would find a host of potential ailments. Your next task would be to refer to the encyclopaedia's entry for the low-down on your illness (real or imagined). I spent endless hours tracing the various potential major and minor sicknesses and injuries that might have befallen me and mine. It was great fun, and I do mean that sincerely.

Not only were Volume One and Two (World Book - Childcraft International, Inc., 1980), in all their minutiae, wildly popular with me, but parts of Volumes Three and Four were, too (World Book - Childcraft International, Inc., 1980). For instance, Volume Three, covering "First Aid, Safety and Care of the Sick" (World Book - Childcraft International, Inc., 1980), had a wonderful section on your 'home care layette', as I now think of it. It had delightful depictions of the first aid kits, medical chests, and so forth, as seen from above. You've probably seen this sort of thing before: On the right will be the array of

bandages, then there might be a few pins, rubbing alcohol, aspirins, sterile dressings, ointments all in their place as you sweep across to the left – like a modern day Wilderness Medical Kit (deluxe edition). The idea being, of course, that the image serves as a checklist for one’s own kit. They even recommended a designated sick room! Do you have one in your house? I don’t. To this very day I aspire to the competence hinted at in those drawings: you can look in my linen closet, and I have the shelves with the boxes of the appropriate materials for the care of the sick. Catch, of course, is that most of the time the sick person being cared for is *me*. We’ll come to this later.

Volume Four covered Health and Fitness. I don’t know that I spent a lot of time with that volume, with the exception of the first section, which saw so much use that the pages have actually, over time, separated from the spine binding. The topic of that first section? The healthy child. From the first words on the baby’s room, through the layette, feeding, burping, bathing, body care, etc., I was engrossed. One might have thought that I was obsessed with babies. I wasn’t. In fact, I didn’t think too much of babies generally until the recent past. I think it was the functionality of the whole section that appealed to me. The idea that a person could have the tools at hand that would allow for the proper execution of the task has always been rather thrilling to me. That much has not changed.

The narrator pauses, switches signs once again:

scene ii 1982-2004: Before

She settles back in for the new narrative:

OK, so that gives you a taste of my early encounters with ideas of health, illness, wellness and care.

Time went on, and new health experiences peppered my life. Highlights include a tropical brown banana spider bite in 1982 (in Southern Alberta, no less: here I learned about toxicology panels and banana trucks from South America); an adenoidectomy the same year (and I learned that, while the doctors might think 2-222s were ok for a seven year old for pain management, my mother had a very different – and disregarded – opinion); a malignant melanoma and skin grafting in 1983 (which taught me about disability, wheelchairs, crutches, and learning to use my foot again. That, and parental terror): in 1985, a meningitis scare, spinal tap and quarantine taught me that force is sometimes used for the betterment of one and all (in the form of being held by four adults while the lumbar puncture was carried out); and a tonsillectomy in 1988 (here I got my first taste of ‘do what the doctor orders’, when I was brought a post-operative grape popsicle, which I refused to eat, and after being force-fed it by a nurse, I proceeded to vomit all over my father. I still think grape popsicles are vile). Additionally, I received an ‘official’ hypoglycaemia diagnosis in 1991 (after self-diagnosing based on my Biology 30 unit on the endocrine system). Other than a hernia repair for my sister when she was seven, neither my brother nor my sister caused much in the way of health concerns. Me, on the other hand – well, I certainly exhibited a penchant, genetically and circumstantially, for variety. What that gave me was an early, and broad, concept of Western medicine and medical care. But that’s my 20/20 hindsight talking, not the ‘me’ of then. None of this, though, was called ‘health literacy’.

More books arrive.

In my twenties I developed a taste for historical and popular science accounts of infectious diseases. The realisation that we are often but an infectious microbe’s-width

away from a host of vicious and macabre deaths did nothing to stymie my reading. It did provide me with a very solid understanding of things like vectors, proximity, herd immunity, critical mass, environmental influences, and life-before-vaccines-and-antibiotics (and after). This knowledge is not to be minimised: perhaps nothing has been so effective in developing my appreciation for all-things-health-literacy as those early, formative readings, in the sense of what is required of an individual to be part of a population.

Years went on like this: when the Internet became ubiquitous (and I still remember that first *Time* magazine cover, the one about the ‘Information Superhighway’), so did ‘new’ knowledge, about everything, including my beloved diseases. For a while I was impervious to this ‘new’ way of getting information. Search engines (if they could be called that) failed miserably to produce anything worth anyone’s time, and so I continued to read books, magazines, brochures, and to talk to actual people, if I wanted to know about something. There was certainly a more relaxed pace – after all, I couldn’t go to the library at 3 am, no matter how badly I wanted to know about Ebola.

More years came and went, and my plans to go to Africa and do relief work around basic health care and literacy (because I was still envisioning such a future, despite financial evidence to the contrary) evaporated when I married. Like so many others, my altruistic intentions fell victim to love. September 11, 2001 came along, and we travelled to New York in October 2001 to visit my future husband’s brother (and future sister-in-law). We were standing in Times Square when the NASDAQ marquis began scrolling, in its disturbing casino lights, the words “The US has begun bombing Afghanistan”, over and over again. All of the fears of wars and bombs, and most especially bioterrorism, took flight. Anthrax was found in the New York Governor’s offices in midtown Manhattan

(where we'd just been), and testing was occurring at his mansion at 138 Eagle Street in Albany. We were staying with our relatives at this time. Their address? 179 Eagle Street.

Returning from our wedding in late 2003, the airport was littered, literally, with neon yellow notices, warning us of the imminent dangers of the SARS outbreak, and the need for vigilance and surveillance – for and of ourselves, and others. I remember stopping to pick up one of these memos, scattered like confetti, and reading it while I walked to baggage claim. When we arrived at home, our television swarmed with images of Tokyo residents masked and scuttling from building to building, as if simply being seen was enough to become infected.

So really, the SARS outbreak in 2003 was merely the infectious disease pandemic variant of the 'man-made' bioterrorism fantasy of anthrax, circa 2001. And they were both superb training for my later encounters with pandemic influenza, H₁N₁, in 2009. This was the world I was a part of, the reality I knew, in 2004.

Here the narrator breaks. Before she begins the next narrative, an array of lights comes up, SR, casting a rosy, homey glow over a set of chairs, with a small table between, and a bassinette. Stacks of books litter the surrounding area. She crosses SR, digs around, finally finds the next sign:

scene iii December 2004 – September 1, 2005: Transition to 'Now'

She settles into the right-most chair, and begins to speak again.

So, I was certainly primed for this kind of exploration, of this thing called 'health literacy', insofar as pregnancy and motherhood were concerned. Of course, like I mentioned, I had other plans for my life, but somehow I've ended up here, talking to you.

This is hardly the ‘relief work’ I had in mind, but I suppose it’s kind of public health and education, sort of.

After being married for a year, we decided we should probably think about starting a family – after all, I was heading into my thirties, and we all know what reproductive minefield age 35 can be. I was well-versed in the refrain of escalating birth defects post-35. I was 30 when our son was conceived, and conception was remarkably easy for us (think of it in terms of “how does next Tuesday at 2:30 work for you?”). The early months were spectacular only insofar as the vomiting goes – the classic ‘morning’ sickness was the ‘morning-noon-night-midnight’ sickness. I was initially prescribed the standard does of Diclectin[®], and over the next few weeks my dosage was increased until we reached what was called the ‘research dosage’. Still nothing. My thought was that, once we were crossed the ‘eight-pills-a-day’ threshold, we might as well abandon hope. Frankly, I was desperate, and after six weeks of violent vomiting, I started taking Gravol[®]. This was my first real encounter with mommy-guilt. The messages I had received were unequivocal: you don’t take medication when you’re pregnant. Period.

My doctor knew, and pointed out, that in fifty years on the market, no adverse effects had been found: But there is always the caveat that the drug was *not tested on pregnant women*. There is always the chance. I went to the Motherisk website to try and find some answers, or at least some peace of mind. The organisation’s by-line is ‘Treating the mother – Protecting the unborn (www.motherisk.org)’. I found this:

The narrator takes out a recipe card, à la public speaking, and reads:

Gravol, an antihistamine, will not increase the 1% to 3% risk for birth defects that is present in any pregnancy and its use in pregnancy is therefore OK. As for possible

side effects, they differ from person to person. Diclectin is prescribed in Canada for persistent NVP symptoms. Diclectin is the safe, approved treatment labelled for pregnancy.¹⁵

So, what am I supposed to get out of this? There are so many interesting words to choose from. Gravol works, but it's not labelled for pregnancy? It's labelled for nausea and vomiting. Of course, pregnancy doesn't equal nausea and vomiting (or NVP, which is what I learned they called it, clinically). Except for, in my case, it kind of does. What about 'approved'? By whom (and under what conditions)? And why isn't Gravol 'approved', if it works? If it's not "approved" does it mean "unapproved" or "unsafe" or simply "the patent was up on that drug ages ago so we don't make any real money off it – here! Try the more expensive brand!" So, what I was left with was the distinctly haunting feeling that I had somehow endangered my baby through lack of scientific endorsement for Gravol.

It is only just recently, eight years after the fact, that I've discovered a book published by Motherisk, called "Nausea and Vomiting of Pregnancy: State of the Art 2000" (Koren & Bishai, 2000). In it, I've found articles that talk about physicians' lack of adequate information to help with NVP (Schofield & MacKinnon, 2000) and articles that outline the safety of Gravol as "not associated with an increased teratogenic risk" (Magee, 2000, para. 8). It would have been very helpful to find this information *before* spending eight years questioning my choice.

¹⁵ This specific quote is no longer available on the motherisk.org website; however, it is still the organisation's stance that Diclectin is the pharmaceutical of choice for NVP. The verbatim quote is currently still available through two separate forums, at <http://answers.yahoo.com/question/index?qid=20090523212023AA4hSeL> (posted by 'Trying for 2', May 23, 2009), and at http://community.livejournal.com/pregnant_/1196901.html (posted by 'NVP Counselor' on May 24, 2005). This information is current as of January 20, 2014.

The information and learning curve – the ‘pregnancy health literacy’ arc specific to the Western middle-class experience – is staggering, at least the first time you go through it. From the moment you find out you’re pregnant (and remember, I’m coming from the standpoint of someone who was ready and able to both be pregnant and raise a child, and somewhat cognisant of the impending challenges), it’s a massive download, to use the modern metaphor. I read the baby books; I showed up at the appointments (all scheduled exactly as they should have been). It felt (and still feels, when I look back) like I was trying to be a very good student of pregnancy: there was a curriculum, and I was the student, and I was trying to get the very best grades. Good behaviour = healthy pregnancy = healthy baby.

I struggled a great deal making sense of the rhetoric around pregnancy diet and weight gain. Never mind just eating a healthy, well-balanced diet. No. That was insufficient for a human baby to form. I wanted “the best”. Never mind none of us can agree on what the “best” is. The Brewer Diet says one thing; the Mayo Clinic another; Health Canada has its own guide.

I went with the Brewer Diet (www.BlueRibbonBaby.org) with this first pregnancy. Instead of the “no more than 25 pounds” weight gain, as promoted with the lovely in-office posters that show you where the weight goes, “8 pounds, baby; 3 pounds, placenta”, you get something that resembles free rein – not a lot of counting calories (though balance is important). I remember it being very much focused on ‘good fats’ – whole milk, yogurt, butter -, and protein. I actually felt *healthy* (as in, ‘not as quick to vomit’). My weight gain after the first trimester (when I actually *lost* weight) was rapid, and I peaked at about 225

lbs. I knew the ‘rule’ about 25 pounds, give or take, of weight gain during pregnancy. I knew the “you only need an extra 300 calories per day” rule. I just didn’t follow them.

There was, so it would seem, an upshot to this. At around the 25-week mark (about June), I was provisionally diagnosed with gestational diabetes. I say ‘provisionally’, because of how the whole situation evolved. After being sent for blood tests, peeing in impossibly small cups, drinking thoroughly nasty beverages to spike my sugar, and almost losing my consciousness and my cookies in the lab’s waiting room, I was informed that I was “maybe-gestationally-diabetic”. I kid you not.

When I showed up a few days later at the Diabetes in Pregnancy Clinic, I had the pleasure of meeting the inspiration for Nurse Ratchett. She informed me that my levels were “sub-diabetic” (but only just barely), and that I needed to re-take the glucose tolerance test (the GTT, for short) for a definitive diagnosis. I flatly refused. I informed her that I had been following a diabetic diet, and my sugars were swinging more and more (which I was tracking, and I had a calendar of my menus and tests), and I *knew* I was gestationally diabetic. I used all the right words. I believed that the GTT was a waste of my time, and the Region’s resources. What followed was a power struggle, one where I was undeniably at a stark disadvantage. Shaming is a very effective tool to motivate action, but an innate dread of revisiting an awful experience can be equally persuasive.

Finally, I asked her point-blank if she was going to refuse me treatment (a prescription for insulin) if I refused to re-test. She reluctantly, and rather insolently, wrote the script. Perhaps the worst aspect of this was that, because of the shared-care arrangements (which you don’t get any option about in the Calgary urban low-risk pregnancy category), I was required to ‘work with’ this nurse for the remainder of my

pregnancy. I got to see her colleague more than her for the remaining months: I doubt this was coincidental.

At the end of the pregnancy, my sugars were increasingly out of control, despite all efforts to manage them – and so, it was decided that I wasn't going to be 'allowed' to go past term. We settled on September 4th, 2005 as my inducement date (also my due date). My son had other plans, and at about 3 am on August 29th (a Sunday) my water broke. No really great contractions began, so we didn't rush into the hospital right then. As morning dawned, we packed our bags and headed to the hospital. After a very unpleasant internal examination (which nobody explains to you, and nobody warns you about), the obstetrician-on-call decided that I was not dilated enough to merit admission, and I was sent home with instructions to come back when things were moving along, or the next morning, whichever came first.

The next morning was no more remarkable – a quick trip to the hospital confirmed that I was no further dilated, so I was sent home with instructions to walk around. Some poor man in at the fish 'n' chips stall at the mall nearly fell over in shock when he asked me when I was due, and I told him I was in labour right that minute. And so Tuesday came and went, no closer to birth - or sleep, for that matter.

Wednesday we went in once again: when they checked me, I was still hovering around 2 centimetres, and my contractions hadn't increased in intensity or frequency. However, given my gestational diabetes and the non-progression, the obstetrician-on-call (the third in three days) decided to admit me. Happily, I got to bypass the congested waiting room because my gestational diabetes graduated me up the risk hierarchy.

Once settled into my delivery room, I got to be attached to a host of machines – a foetal heart monitor strapped around my enormous belly kept me stationed in my rocking chair, and the IV dripped away the hours. They monitored me for something they kept calling ‘D-Cells’. Like the battery. I’ve only lately figured out that they were saying “decels”, as in “decelerations”, and they were referring to the baby’s heart rate during contractions. Am I the only one who didn’t know this?

Late that afternoon, the obstetrician (a different one *again*), decided that I wasn’t progressing, and that it was obviously *stress* (!?!) and that I should get an epidural. Now, I wasn’t one of the purists who wanted an all-natural birth, in the sense that I wanted no medical interventions – like drugs. I didn’t go out looking for drugs, certainly, but after three days of quasi-labour, drugs seemed a sensible next-step. As far as I knew, caesarean section delivery required *more* drugs. So, at this point, even though the alternative reading of “you are not doing what’s best for your baby – he’s coming into the world before he’s ready and with drugs in his system – you are a bad mommy” was playing through my mind, I thought it best that he actually make it into the world and get on with things, rather than this three-day limbo-purgatory we had gotten ourselves into.

There’s this awful moment when they give you the “epidural pep-talk”, which goes something like this: “You must curve your spine out and remain motionless. If you move even the tiniest bit, the needle could go astray and damage your spinal cord, resulting in paralysis.” To put this in context, you are contracting, exhausted, demoralised and now terrified. And God help you if you accidentally looked at the needle.

I was able to endure the pain of the needle, obviously. Shortly after, when the pain began to subside and the blissful numbness kicked in, I learned another fun tidbit: the

fentanyl that they administered in the epidural had the unfortunate side-effect of making it feel as if a million ants were crawling on my skin. And because you can't actually *feel* how much you are scratching once the numbness sets in, you run the risk of tearing your skin open if someone doesn't physically hold you back.

In time, the exhaustion took me, and I actually slept for a few hours. When I awoke, it was right back into the 'let's have a look and see how dilated you are' queue. This is a fun spectator sport, it turns out. The number of individuals coming in and out of your room, unannounced, is difficult to track. There comes a point when any semblance of modesty, never mind prudishness, leaves the building. It seems like everyone comes for a look-see.

At around midnight things started to pick up, labour-wise. As things went along, a senior nurse came in to check me, had a look, and said "Oh, she's hours away. I'm going on break." I very clearly remember thinking: "The hell I am." At about this point, things really got going. The younger nurse that had been left in charge (quietly doing paperwork at a table next to my bed) took a look after a few minutes, ran out the door, and brought in yet *another* nurse, who started to give me pushing instructions. I wasn't very good at it. So I said, "Just tell me exactly what to do." She responded, "Push as if you're aiming right here" and she poked me in a very specific, very delicate spot. "All right then." And push I did.

She started to coach my husband in counting. I should add an important aside right here: My husband and I had skipped our labour classes. Both of us were weirded out at the thought of sitting in a room with a bunch of strangers while practicing huffing and puffing. I had read the books, though. My husband didn't even pick the books up. So, when he

started trying to count with me, he was already 3 counts behind: “1-2-3...” (I shook my head violently) “Oh, 7-8-?” (I growled quietly). I don’t think the counting continued, at least with him, much beyond that.

I had been told that the on-call ob/gyn (my *fifth*) lived only 10 minutes away and that ‘she’d be called when it was time’. The senior nurse that had pooh-pooed my earlier attempts walked back into the room at about this time (2:10 am or so). She took one look and said, “We need the doctor *now*.” *Ha! Take that!* I thought. About ten minutes later the doctor walked in, the nurses literally threw her gown on, and she caught our son. I have the clearest memory of her, forearms barely in her scrubs. Hope she wasn’t wearing anything nice.

Our son celebrated his birth with a fountain of pee. It seemed as if all nine months of incarceration were being flung upon the world in one fell swoop. I personally found it funny, but the medical staff that slid all over the floor did not feel the same. A bit of ointment for the eyes, a quick once-over in the plastic bassinette, and my 9 lb 15.6 oz baby was placed in my arms. The adventure was about to begin. Did you know, in scholarly circles, that it is only at this moment that I actually get to call what I’m doing ‘mothering’?

Are you exhausted by this last outpouring? I am. I’ve been aiming to make sure that you had really clear pictures of the niceties of pregnancy and delivery. Obviously, I’ve left a very great deal out, and for that you ought to thank me.

Returning to the birth: moments after Jack was born, a nurse came in for a lactation consultation. I had every intention of breastfeeding, as I was fully swayed by ‘breast is best’ campaign being waged upon mothers in our health region (this is told retrospectively, of course – at the time I hadn’t the foggiest notion of how my thoughts and emotions had

been manipulated under the auspices of ‘education’). I come from a family of non-nurses: I wasn’t nursed, my sister thought breast-feeding was slightly ‘icky’, my mother-in-law was running a farm while having children. My grandmother thought it was what poor people did. My best friend abandoned the practice at six months because she needed to go back to work. I didn’t have a lot of supportive or knowledgeable models to work with. So the nurse came in, and without asking me about my background or my intentions, announced: “Let’s see if we can get this baby to latch!”

Another piece of dignity tossed by the wayside, I proceeded to allow the nurse to position Jack, mostly like a football, and push his little mouth onto my breast. It took him a few tries, but he got it. She left us to our own devices, advising us to engage in kangaroo-care (placing your child in skin-to-skin contact) in her absence. So we nursed, and cuddled, and nursed, and cuddled, until I truly felt like a zombie. He seemed happy to sleep, and I too fell into a coma.

Five hours later my husband showed up, rested, showered, coffee-d and chipper. Needless to say, I welcomed him with a reservation bordering on open hostility. He mostly held Jack and watched me. When Jack had his first meconium poo (also known as the tar poo), I did something awful: I told the nurse I didn’t know how to change a diaper. In truth, I knew exactly how to change a diaper, and exactly what to expect on that first bowel movement. My husband was thoroughly scandalised, but I figured that I was there anyways, might as well let someone else have the fun for a bit. He hadn’t offered, after all. (I feel bad about being so cranky during this time, now that I know what was going to happen next in our lives – but this is only hindsight).

I had felt, right from the start, that Jack's nursing wasn't going well. The nurses insisted I was fine. I disagreed, and argued for a 'supplemental' bottle. Jack inhaled it. I asked for another. The nurses raised their eyebrows, but didn't say much – the child was obviously hungry.

That morning it was time for the first bath. If you've never had a baby before, nor been around a newborn, let me tell you: they're downright crusty. Off we went to the nursery. The nurse insisted I watch the bath, so she could 'show me how.' I knew how. I told her I knew how. She ignored me. Maybe word of the tar-poo incident had leaked out.

She proceeded to bathe a very ticked-off Jack under those demonic red heat lights. It was all I could do to not grab him out of her hands as he wailed. When she finished, she thought he felt cold, and took his temperature: 36.4°C. She told me he was too cold and that he had to stay under the heat lamps (Note: he was now livid – he was generating enough angry body heat to warm a hatchery, but his core temperature wasn't going up). I tried to tell her that he had a lower-than-average temperature at birth, it hadn't changed, and that I too had an historically low body temperature. It was only after 40 minutes under the lamp, with no change whatsoever, that she began to consider I might be right (but she could chart she followed protocol). She huffily handed my hysterical baby over to me, and off we went. This was to set the tone for our future medical experiences, he and I.

We were released the next morning, Friday, after we could prove that we had a properly installed child safety seat (what if you have to take a taxi or the bus? Or walk??). I remember walking into our home, setting the car seat on the chair and then stopping. This was a world I didn't know anymore, in a house that was no longer the same.

In the next few days I was regularly harassed by the public health nurse who checked me for post-partum depression, haemorrhaging, the viability of my support network, and my breastfeeding prowess. I passed on all counts save one: breastfeeding. Jack soon lost nearly one pound of his birth weight, crossing that magical ‘lose no more than 10%’ threshold established for newborns.

I began having to document all of his ‘pees and poos’: time, colour, all in a nice little chart. I stressed out that I didn’t have the exact times, I stressed out that he didn’t have as many bowel movements as he was supposed to in the ‘regular’ scheme of things. Turns out, all these years later, that’s just Jack. The nurse wanted to see my paperwork. She finally conceded, somewhat sharply, “Well, I suppose you are going to have to supplement with formula”. Off I went to get all the gear, and no sooner did I do that, but Jack gained back the weight and stopped screaming at feeding time.

The most negatively memorable incident from this time happened at Costco. As it happened, my formula-of-choice was available for a discounted price, so, as I was no longer contributing much to the family’s income, it behoved me to practice parsimony. After loading up on as much formula as I thought we’d go through before the expiry dates (I was staggeringly wrong in my calculations, by the way), we proceeded with our receipt through the gauntlet of highlighter-waving, bitter Costco minions that permit exit from the building. Upon presenting my booty and my receipt at the waiting employee, she stared at my cart, looked me straight in the eye, and levelled me with: “You ought to be ashamed of yourself. Feeding your baby formula!” I couldn’t even process this, let alone muster a scathing response. I know I should have said something, raised Cain, yelled for a manager,

did *anything*, but all I could do was waddle out of the building, trying to fight back my tears and shame, and get to the safety of my vehicle with my baby.

This would ultimately be a rather uneventful examination of health literacy's varied meaning(s) if one plotline existed. However, a second complication was on the horizon that was going to bring health literacy as a concept worthy of deeper exploration to the forefront of my world. I had had the altogether delusional thought that it was a great time to do another degree, what with being at home and all. I was most of the way through my application for the PhD program in Education (curriculum, teaching and learning as my specialisation) when Jack was born that September morning in 2005.

The next few months were relatively uneventful: we slept and ate when needed, and I sent in my graduate school application. I received my acceptance; I negotiated with my mother-in-law for a bit of childcare for the next Fall, and bartered with my husband to watch our son so I could do my online Methods courses during our summer vacation. I was not much more than machine: I read all the pamphlets, books and labels that came across my path. I got up for all the night-time feedings so that my husband could sleep so he was 'fresh' for his work. I cooked, cleaned, mothered, and thought I was a brilliant success. Then April 18th, 2006, happened.

Here's where the plot complicates itself further: If you're keeping track, you'll notice I'm about to tell you about the *third* major change that occurred, alongside new motherhood and new academic pursuits. Two would have been sufficient to give me pause: but, unlikely though it may seem, number three loomed on the horizon. I just didn't see it coming. I didn't choose it, not like the others.

Lights come up on SL, on a hospital bed, empty. Small stacks of books are in sight. The light is the cool, bluish colour of clinical facilities. The IV flashes behind the bed. The narrator stands, and as she walks over to this area, the 'home' lights fade to black. She picks up the sign on the bed, and shows the audience:

scene iv April 25, 2006, 'til The End of Time: Learning to be 'Patient'

After tossing the sign behind the bed, she lies down on the bed, stock-still. There she remains for an uncomfortable length of time. About the time the audience begins to fidget, she raises herself on the bed (it is an electronic bed, where the head and foot areas are automatically controlled). Perhaps she even plays about to find the "right" height, before she addresses the audience once again:

I had been swimming in a murky, subterranean world of morphine and pain and, as I surfaced, I discovered that there was a lot of traffic running through my hospital room. Sure, there were the normal nurses, lab techs and janitorial staff, but it was the doctors, – normally, one would expect one doctor, once a day, making rounds and adjusting treatment – no, this time there were lots and lots of doctors, and at all times of the day. I was the unwitting star attraction in a very bizarre circus.

At this point, I had been hospitalised for a week, and during that time I had been treated to what my family calls (only now) a '6-tube event': catheter, oxygen, NG then NJ tube, IV then central line. I was only now stable, except for the pain, and the cause of this bout was undetermined.

No one bothered to tell me why there were so many physicians there – I mean, I knew by this point that I was very sick, sure. I'd quickly realised I'd lost a week of my life somewhere in the void – but that certainly didn't account for my popularity. It was about

the time that one physician, South American judging by accent, asked if one of the other doctors could touch me that I clued in: these were *students*.

I began to piece together that I was on the teaching floor – and that I had a group of residents following around an attending. They were on their internal medicine rotation, and I was (as my boys would now say) the “big, fat, juicy” mystery on the floor. No one knew the cause of my acute severe pancreatitis (for that’s what it had been) – no alcoholism, no gall bladder problems –, but my attack was so severe that, in the early days a diagnosis of necrotising pancreatitis was floated, and some end-of-life scenarios were debated, much to the terror of my husband. Sure, the default diagnosis was “idiopathic” (which, I’ve come to appreciate, means ‘no f%^o^*ing idea’), but even at that there are degrees of interesting within the realm of the idiopathic. Some mysteries beg for investigation, others not so much. For instance, an idiopathic skin rash – not so exciting; but an idiopathic pancreatic attack that struck someone like me (very low risk) out of the blue, well, there might be something really interesting going on my case. So one set of residents, then another (I was lucky enough to be there during changeover from one rotation to another) mulled over my case.

As an aside, let me say this about pancreatitis: the pain is extraordinary, even otherworldly. I have had more than one medical professional say, without hesitation (and with a wince), “That is the most painful thing a human can have.” While I have a hard time fathoming how limb severance could be *less* painful than pancreatitis, I also have no desire to disprove their theory with my own data. What I do know is that pancreatitis, when in full bloom, offers an all-encompassing agony that cannot be alleviated by any

form of positioning or praying. Breathing is so excruciating that you do as little of it as possible. So this is where I found myself that April.

In between the ebb and flow of the pain, in those moments when a semblance of lucidity was available to me, I entertained myself by listening in on the discussions and debates that occurred both within and without my room, primarily about my ‘situation’. The charting computers were just outside my door, and the larger percentage of doctors and nurses are nothing if not indiscrete in their hallway conversations. One blessed person in this bunch of fourteen people came up with a differential diagnosis of hypertriglyceridemia, at the time thought to be a rare disorder where the body doesn’t manage triglycerides effectively. As the amount of triglycerides elevates in the blood, the risk of pancreatitis rises commensurately. When this resident offered this differential diagnosis to the attending, he was greeted by a frown. But the resident pushed on, arguing that, despite its rarity, I fit the profile, and that if I was treated for it and didn’t respond, there was no harm done.

The primary course of action was to treat me with fenofibrate, which essentially raised the level of the enzymes that break down triglycerides. My triglycerides came down (farther than they had on just NPO), and the pain began to level out – but not disintegrate, I regret to say. My earlier experiences in having a very high painkiller dose threshold (remember those two-222s when I was seven?) held in this case: well into the second week of hospitalisation they were still trying to get the pain under control, so much so that they brought the Pain Management Team in to consult, and they inserted ports into both my thighs (which hurt far more than they helped) for administering pain medication. They even tried, later on, oral morphine – and the taste alone is enough to dissuade addiction.

Over the ensuing weeks, my mental state began to disintegrate: my husband had brought a picture of our baby for me to keep at my bedside, and even though he brought Jack to see me in the mornings (before he dropped Jack with his grandmother) and the evenings (when he picked him up after work), the visits were painfully brief, and I was in hysterics for hours afterwards. I would often pick up Jack's photo and begin crying inconsolably. More than once nurses caught me cradling the picture and sobbing. It is exceedingly difficult to heal when your heart is in pain, I discovered.

Because of this, the doctors decided amongst themselves to try weaning me from morphine (there's no cold-turkey when you're on as much morphine as I was) in order to release me ahead of what was planned. The basic calculation was "What will do less harm?" Going home with pain medication and implementing a large number TLCs ('Therapeutic Lifestyle Changes') (Pelic & Lee, 2006) ahead of schedule, taking the chance of relapse, or keeping me in the hospital for the 'full' length of treatment, and risking my complete mental breakdown? I was released after one month, rather than the standard two, and I was beyond ecstatic. I had my life back, even though it was much changed.

I didn't eat much and I was exhausted most of the time, but I was home. I spent much of my time in fear: dread that every twinge was a harbinger of a relapse. I spent every imaginable moment with my baby, and I didn't do much that would require me to go far. Initially, I was left to my own devices, with a lifetime prescription of medication, and quarterly lab tests to monitor my triglyceride levels. It would have been one thing to be very sick, recover, and move on (still, always, bearing something of a scar). But this, I knew, was never going to get 'better', insofar as going away, but it was also within my ability to keep myself alive and functionally healthy with Therapeutic Lifestyle Changes –

but it was up to me. I learned that I had pancreatic scarring, and that with every subsequent recurrence of pancreatitis, more scar tissue would build – and at some point, there would not be enough healthy pancreas would be left to meet my body’s needs for various substances, and insulin dependent diabetes would greet me at the door.

Lights come up CS, and along the apron. The narrator holds up the placard (which was under her pillow):

scene v August 2007: A Lesson in Mortification

The narrator delivers this next segment while ever so cautiously and precariously manoeuvring out of the bed, and onto the floor, on all fours. She navigates the distance to CS and apron in painful, sporadic movements. Her attitude remains chipper. As she progresses, the SL lighting fades to black. There is a small wall of books she has to surmount on the apron’s edge.

In mid-August 2007 I celebrated one of my lowest moments. I say this, of course, with dripping sarcasm. My husband, nowadays, jokes about the day I searched the lawn for my missing ring. Except I wasn’t ‘searching’ and there wasn’t any ‘missing ring’. It was our official front for why I crawled from where our Jeep was parked at the curb, across the grassy boulevard, up the sidewalk, up the concrete steps, and over the threshold of our home, in full view of all passers-by. And when I say ‘crawl’, I mean it. It was full on, hands and knees, snail’s pace, hangdog crawling.

This is your introduction to my *fourth* major life event, in less than two years, that contributes to the plot – the health literacy mystery, if you will. It all began when I was taking Jack, just about to turn two, to his optometrist’s appointment just before closing. All was perfectly normal as we packed ourselves into the Jeep and drove the short distance to

the office. When we arrived we discovered that the office was blacked-out: someone had just hit a light pole on the main road, wiping out the power to a whole section of the city, including ours. This, of course, meant that a technology-driven optometrist's office was out of commission, and closing for the evening. So, I turned to take a very annoyed toddler (who did NOT want to leave the toy area) back out to the vehicle. As I hoisted him onto his feet, I was nearly brought to my knees by a back spasm. I held my breath and strong-armed him (and myself) out the door and into the vehicle (I didn't want anyone to know I was in pain).

Once I got myself into the vehicle (which frankly amounted to an act of God), I knew we were in deep trouble. I had had numerous run-ins with back spasms, but this defied all description. Very carefully, I managed to drive Jack and I back to our home, screamingly aloud at every little wrinkle in the road, and parking (thankfully) in front of our house. And there we sat. I quite literally could not move. We were blessed with two pieces of luck in that moment, for which I will always be grateful: first, I had Bluetooth in the vehicle so I could call my husband without moving anything more than one arm, and second, we had a DVD loaded in the player, and the screen was down, which meant I could let Jack watch to his heart's content, again only moving one arm to control the show.

I called my husband to explain that I needed help, and desperately. He let me know he was on the 17th hole, and he'd been back when he was done. I don't recall the exact words that I used, but I think that the general gist was that I would do him bodily harm if he didn't come home immediately. At a minimum, I didn't understate the case.

When he arrived, he whisked Jack out of the vehicle and into the house, and came back to check on me. The conversation went something like this:

“Can I help you?”

“No.”

“Do you need me to carry you?”

“No.”

“What do you want me to do?”

“Nothing. Watch Jack. Open the door.”

He opened the door and stood back. I didn't move. I said, “I'll be right there.” This was meant to both let him off the hook, and to remove the possibility of an audience for what was about to come. As he walked back up the walk, I gingerly used my hands to lift my left leg towards the opening. I'm pretty sure that my profanity was spectacular.

Once my left leg was positioned, I attempted the same thing with the right. This proved more difficult, because I no longer had the stability of the back of the seat. Again, more obscenities. Eventually (and we're talking 10 minutes of 'eventually' here) I got my legs to face the outside of the vehicle. Paul came out to check on me. I may have hissed.

Now came actually getting off the seat. The driver seat in my Jeep positions my feet about a foot off the ground. That one foot might as well have been climbing Everest. I dribbled from the seat towards the ground, praying the entire time that when my feet made contact the rest of my body would somehow keep me up. Otherwise I faced the rather unpleasant scenario wherein I would be lying in the middle of the most-trafficked road in the neighbourhood, smack in the middle of the bus route. Thank god the school across the street was closed for the weekend.

Miraculously, I didn't buckle when I landed, but neither did I stand, precisely. I was more smeared against the Jeep than anything. It was blessedly warm, and I felt I'd

accomplished quite a lot for the day, so I was content to simply (and rather bizarrely, from a bystander's perspective) stay pasted to the side of the vehicle. Paul appeared around the edge of the vehicle, eyebrows raised, and I scowled. I began to inch my way along the driver's side of the vehicle. When I reached the back, I bravely (and, it turns out, recklessly) attempted to turn. That didn't go well. Thankfully, the back of the vehicle has handles, presumably for decoration, but on this day they served beautifully as the handholds that kept me from collapsing. I suspended myself by those grips while waves of pain rippled up and down my useless legs.

My husband's head kept popping into view at our screen door. He knew better than to ask if I need help at this point: truly, had he tried to touch me or, god forbid, lift me, I would have started shrieking hysterically. After the spasm subsided a small bit (and before my biceps ruptured), I began the long journey along the backside of the vehicle. I aimed exclusively for the opposite handlebar, curbside.

Once situated at the corner of the vehicle and the grassy boulevard, I faced a new challenge: I couldn't walk, so how was I suppose to negotiate the forty feet to my front step? I scanned the area for other people, and then, assured of the privacy of my coming indignity, I half-slid-down-the-side/half-threw-myself forward onto the grass. It was a sort of fold and fall cum slump. And there I lay. I know there was no one about, because honestly, such a spectacle witnessed by another would only have led to an emergency call, either to the paramedics or to the police – I'm not sure which.

After what seemed an eternity, I hatched my plan. If I could get on to my hands and knees, then I could creep my way up the sidewalk (on the cushy grass, thank the Lord), under the auspices of "searching for my ring". It was plausible, and it was decidedly

preferable to lying prone on my front lawn. I got my hands and knees under me, and began the laborious job of hauling my seizing body up the sidewalk. Another little wave from my husband, from behind the screen door, and a thumbs up. Jesus.

You might ask how long this whole affair took, and the truth is I don't really know. I know it took nearly an hour to go from the driver's seat to the front step, and I don't even remember getting up those steps, or over the threshold. I do remember lying facedown, motionless, on my entry floor. I also recall my toddler coming up to me, getting on his hands and knees and putting his face really close to mine to ask "Mommy, why are you on the floor?" I'm pretty sure I answered something along the lines of, "Oh honey, mommy's having a bad day. I'll get off the floor soon."

In the next few hours, as I continued to lie in the doorway, my husband brought me Tylenol, because I was too fearful to take anything stronger. I suspected I was pregnant again, but it was too early to tell (we're talking six days pregnant). My husband brought me some stew, and I somehow got that down, lifting my head and my hand, briefly and painfully, to scoop it down. I probably should have skipped supper. My son, after being fed and bathed, came to wish me goodnight on the floor. I'm pretty sure that he thought he would find me there, chipper as always, next morning.

By 9 pm, I decided that this was indeed pathetic, and I had to either get up the stairs, or call EMS. I began once again the inchworm crawl, this time more like a slither, to the stairwell. Once there (another 30 minutes gone), I had a choice: I could attempt to crawl up the stairs or I could try to get my arms up and around the banister (a sturdy thing with its own railing and newel post), and then hoist myself, arm over arm, up the stairs. I went with Option B.

I distinctly remember feeling like I was in one of those horror movies, the ones where the victim has had her legs cut off and she's still trying to get away while the killer taunts her and tails her retreating steps (of course, 'steps' is something of a pun, in this case). As I dragged my lower body up those steps, I could only marvel at the mind's desire to continue, and the body's compliance, even in the face of such adversity.

The memory of the long crawl down the hallway is a black hole, as is the process by which I got myself onto our oversize bed. I'm not sure where my husband was during all of this. I can only assume (and hope) that he was hiding. Imagine my bitterness when, after somehow getting onto the bed, I realised I needed to pee.

So began a 2-week back 'spasm' that shackled me. My mother came to watch my little one while I lay in the bed, contorted by the contractions that rippled through my buttocks and lower back. My leg would actually pull back from my body, trying to curve back towards my head, and all I could do was scream and cry and pray. In writing this, I do have to ask myself why, at any point in this whole debacle, I didn't call the paramedics. Surely this qualified as an emergency. But truthfully, it seemed rather pathetic to call 9-1-1 for a back spasm, even one as spectacular as this one.

By the way, in case you were wondering: I *was* pregnant.

The narrator, having been stationed on the apron, now gingerly gets up, and picks up the sign that had been lying next to her. It reads:

scene vi December 2007 – April 2008: Mistaken Identity

During this portion, any movements the narrator makes are with the distinct waddle of a pregnant woman. We notice stacks of articles, pamphlets, and other books, scattered about the stage.

I was perhaps 25 weeks pregnant, round as a basketball, when I walked into the cancer centre. As I walked towards the elevators, I tried to seem confident and comfortable, but I'd never been to such a place before: the gaunt faces and colourful headscarves distracted me. I desperately tried not to stare; but my eyes kept flitting back to them. It was then I realised that, while I tried so intently to avoid staring at others, they were staring at *me*. My thoughts were something like: "Why are they looking at me. Am I being rude? Am *I* staring?"

But then I noticed something more. I noticed the look in peoples' eyes. It wasn't anger, resentment, jealousy, territoriality – it was something I had never imagined, never anticipated: it was sympathy. Compassion. Sadness. And it was for *me*.

And then it hit me, and I stopped. Instantly I saw how I must look. Walking into the centre, a bit confused, trying hard to keep my eyes to myself, trying to read signs nonchalantly, all the while heading towards the elevators and the treatment floors – I was alone, I was heading for the place where the oncology patients go – not the visitors—, and I was very visibly pregnant.

I desperately wanted to call out that I was ok, my baby was ok – we just had a little problem with a genetic condition that we needed to sort out, and the best equipped people to help were the oncology nutritionists because of their work with specialised diets for those with compromised digestive systems. I did not have cancer: far from it. But hypertriglyceridemia can only be controlled in two ways: the first is with medication, the second is with diet.

How had I arrived here? you ask. Well, post-diagnosis in 2006, we were advised to forego having any more children. Strongly advised. And yes, it is now December 2007, and I am pregnant.

Before you chalk this up to flagrant medical disobedience or the ‘oops’ factor, let me say this: our decision to continue building our family was neither taken lightly nor quickly. We had originally accepted this medical advice as gospel. But after a while, I couldn’t move forward without asking more questions. I asked our family doctor what it would take to have another child, given my ‘challenges’. She admitted she did not know, but recommended that I take my queries to a specialist. Originally, she envisioned that I’d see an endocrinologist. Eight months of medical consultation (count two endocrinologists, one gastroenterologist, one high-risk ob/gyn, one high-risk diabetes-in-pregnancy clinician, a nutritionist, and our GP) later, we received or, perhaps more accurately, we were deemed to have given ‘informed consent’ to have another child.

We knew several things embarking on this path: due to the rarity of both the disorder and the diagnosis, as well as the even smaller number that are women, and child-bearing women at that, an almost complete dearth in research or clinical examples were available. My team knew of two women that had ‘successfully’ carried children in my area – one to 28 weeks, the other to 32 weeks. Any others (known) had spontaneously aborted, or had to have clinical abortions because the mother’s life was in danger during a pancreatic attack. I was given about a 50/50 chance of developing pancreatitis, and then a 50/50 chance of surviving that attack.

This was thanks to the relationship between pregnancy hormones and triglycerides: apparently, at around 26 weeks of pregnancy, triglycerides naturally rise dramatically in the

mother. This is unproblematic with most. I, however, am an exception. My threshold for elevated triglycerides (meaning the point at which my pancreas pitches a fit) is about 5.0 mm/L, which is high, but not abnormally so (and certainly not generally indicative of pancreatitis). Normal levels by the third trimester of pregnancy can rise by 200-400%, I was told. You do the math. To complete the picture, my triglyceride-lowering medication is a Level C Risk in Pregnancy drug. Level C Risk means (*takes out another recipe card and reads*):

Animal reproduction studies have shown an adverse effect on the fetus and there are no adequate and well-controlled studies in humans, but potential benefits may warrant use of the drug in pregnant women despite potential risks (U.S. Food and Drug Administration, n.d., p. 50).

One of the endocrinologists advised me to take my triglyceride medication. Mind you, this particular specialist saw me in his office, didn't look up at me once during the appointment, and scoffed at my fears – as in actually laughed when I expressed my concerns. The second (seen about a week later, due to a glitch in the referral system), who did a complete clinical assessment, looked at my history, and took about 45 minutes with me at the appointment, told me to avoid them under all circumstances. Who would you trust?

To summarise: my trigs (to use the short form) go up, my pancreas flares up – my medication brings them back down. My diet, and other so-called 'TLC' measures (remember, that stands for 'Therapeutic Lifestyle Changes') help make the fluctuations less severe, to some (relatively unknown) degree. In the absence of the medication, my diet becomes the greatest mitigating factor. So, here I was, modifying my diet at the Cancer Centre.

What a contrast from the Baby Butter Diet. In Jack's pregnancy, I had enjoyed the largesse of a diet that allowed me to eat well and widely. With this baby, and the spectre of a nature-induced pancreatic attack on the horizon, I was soon 'prescribed' nutritional beverages, because my weekly labs had shown that the numbers were creeping up more every week. This was triglyceride-management-strategy No. 1.

Now, 'nutritional beverages' sound fairly innocuous when stated aloud, but they deserve a bit more vivid a description: 'Nutritional beverages' are designed to deliver maximum nutrition to someone who needs both a controlled-type and -amount of food. Sometimes they are used as dietary supplements, and sometimes they are utilised as nutritional replacements. They taste like shit. Or what I imagine fruity shit might taste like. They have precisely calculated amounts and types of fats, carbohydrates and proteins, and nutrients (vitamins, minerals, etc.). They are more a pharmaceutical than a food. The manufacturers have been overly hopeful in naming their flavours - 'orange' and 'berry' and 'vanilla', none of which bear much resemblance to reality. One maker even concocted a 'pudding'. Now, the really funny part was that the packaging (hence the marketers) couldn't even bring themselves to paste the ubiquitous 'great tasting' moniker on the label. No, even they couldn't do it. All they could muster was 'Good Tasting' – beside the 'Improved!' So, they had 'improved' it to 'good tasting', and even that was a bald-faced lie.

Strategy No. 2, should the 'nutritional beverages' fail me, was tube feeding. Let me paint the picture for you: Basically, a tube is threaded (while you gag and try not to vomit) down your oesophagus (through your nose) and depending on where they put it and where

the prongs are placed, you can have one that feeds your stomach (NG tube), or you can have an NJ tube (one that bypasses your stomach entirely). I have personally enjoyed an NG tube for draining, and an NJ tube for feeding, back in April 2006.

And that brings us to dietary strategy No. 3. If ‘nutritional beverages’ and tube feeding failed to keep my triglycerides down, then intravenous feeding was the last resort. You’re fed through a central line (parenteral nutrition) or an IV in a limb (total parenteral nutrition). I have had a tunnelled catheter – so I have an appreciation of what this would mean.

So here I am at the cancer clinic, trying to look comfortable, trying to adjust to thinking about food differently. From the ‘baby butter diet’ for Jack to the ‘nutritional beverages’ for Noah, I was relearning how I needed to think about nutrition, health and the wellbeing of my babies.

The narrator now waddles her way back over to the bed (SL), as the lights come back up. Now there’s a curtain placed behind the hospital bed, for “privacy” with the other bed. She holds up the sign:

**scene vii Easter Monday, March 2008: The Myths of Freedom of Information,
Protection of Privacy, and Informed Consent**

The narrator climbs back onto the hospital bed, trying to get comfortable. Overhears the following, from behind the curtain (voiceover from offstage):

Male voice, stern: How do you feel?

Female voice, small, panicky, mumbled.

Male voice, louder, harsher: HOW DO YOU FEEL? (*Pause. Annoyed.*): Mrs.

P---, I need you to answer me.

Now, the male voice, tone change, talking to someone different: What did she say
when they brought her in?

Another female voice - cold, clipped, quiet, still unclear.

Male voice, pushing: She said she had pain? Where? For how long? (*We can't
hear the answer.*)

Male voice, harassing, fast: Mrs P---, where does it hurt? Mrs P---, where is your
husband?

*First female voice, the 'patient', more sounds, attempts at words, sounding timid,
ashamed.*

Male voice, frustrated: Nurse S---, where is her husband? (*Unclear words.*) Why
isn't he back from admitting?

Now we hear the cold female voice clearly: I'm not sure his English is good.

Male voice, demeaning, increasingly louder: Well, is it good enough to answer
questions? Mrs. P---, I need you to answer my questions. How long have
you been feeling this pain? How many weeks are you? Who is your
doctor? *Now, to the cold voice:* We need to get her husband in here. Can
you send someone down to find him?

Huffing, shuffling, doors open and close.

Male voice, authoritatively, matter-of-fact: Mrs. P---, I'm going to feel around a bit.

Sudden gasp, sudden flinch, fleeting movement behind the curtain.

Male voice, heatedly: You need to lie still. I need you to lie still.

Whimpering.

The door opens.

Male voice, relief, demanding: Mr. P---, we need you here. How long has your wife's pain been going on?

No response.

Male voice, pitch rising: Half a day? A few hours?

No response.

Male voice: Has she been perspiring?

Now, another male voice, accented: What?

First male voice, again: Perspiring.

Cold female voice, offering: Sweating

Silence.

First male voice, authority giving way to sheer fluster: Perspiring. Sweating.

SWEATING!"

Now, another approach: Who is your wife's doctor? Does she have a doctor?

Male voice, accented: You are her doctor.

First male voice, a strangled growl. To the cold female voice: Go and see if you can find a chart for her. She should be in the system now. Get the monitor on her, watch her vitals. I'll be back in a bit.

Swoosh of curtains.

*Now the narrator changes focus: the doctor is "in the room" with her. She responds to the **invisible** doctor's questions, which are played from offstage:*

Doctor, still terse: Mrs. Vander Valk. It says here you are having pain. What is going on?

Me, matter-of-fact, terse in my own right: I'm here because I have familial

hypertriglyceridemia with a history of pancreatitis with elevated trigs. My triglyceride threshold is very low, and we've been trying to manage it without meds, by diet only, for the duration of the pregnancy. I'm now starting to experience pain and discomfort, so I need my trigs checked – they were already elevated to near the threshold (about 5.0 mm/L for me) last Thursday. I was told by my endocrinologist and ob/gyn to present here if this happened, for assessment. I'm 33 ½ weeks. I'm here alone. My husband is home with our son.

Doctor, caught up short, continues: Where is the pain?

Me, maintaining (what I hope) is my aloofness: I'm feeling pain in my upper left quadrant through to my back. I'm nauseated. I can't control my blood sugars.

Doctor, to the invisible 'other': Call the lab, get her workup. It will be a while before we have the results. We'll put the monitor on, and have a look at your baby. Let's get a line in her.

Swoosh of curtains. Blackout.

When the lights come back, the narrator is in a hospital gown. An IV pole is by her side. The separator curtain is gone, and the lighting is meant to indicate daytime. Her computer is on a table in front of her. She types, then pauses briefly to hold up a sign (not particularly acknowledging the audience):

scene viii March 2008: Playing the Odds, or The Home Stretch

Continues typing. After a period, she begins to read aloud her typed words, contemplatively:

I cannot hide my annoyance.

I am currently sitting in my room in the antepartum unit of the hospital, at 34 weeks 6 days into a high-risk pregnancy. I have been here for 5 days now, admitted because of the warning signs of an impending episode of pancreatitis. It seems, for now, that the attack has been avoided.

Have I also mentioned I have gestational diabetes? And that between me and the experts, we can't seem to control the extreme lows (the ones that are particularly bad for the baby)? The diet for hypertriglyceridemia is extremely low fat and calorically-restricted. The diet for diabetes requires fats and proteins to balance carbohydrates against insulin and blood sugar levels. We dance around diet a lot.

Oh yes: my baby seems to favour a transverse lie, and if he continues in this position, we, he and I, risk rupture and cord prolapse during delivery. Which, of course, can lead to "adverse outcomes" for my little one and me.

I have been averaging three medical appointments per week, for 34 weeks, in order to monitor my and my baby's condition, because of the supposed rarity of my genetic condition, and the risks associated with pregnancy. Add to that travel time, and waiting time. As an added bonus, my condition is so uncommon that I spend huge amounts of time educating medical practitioners about what it is, what it means, and so forth, before we can even get to the substance of the clinical encounter.

I have a beautiful little boy and a husband to care for, and between domestic responsibilities, clinical requirements, dietary management at home, pain and stress, I am tired. No: I am exhausted.

Two weeks ago my triglycerides exceeded our established threshold, and I started feeling miserable. After taking me off all 'food', and bringing the numbers back down, we slowly re-introduced food, only to find that it still made me feel rotten (though did improve diabetic control). A week into this challenge, I decided to present at the labour and delivery unit of my hospital for assessment, and hopefully admittance. My team of specialists had warned me that this was likely to happen, and it did.

Now that I've been here for a few days, I feel better in many ways, and the same in others: better because my triglycerides seem to be stabilising; better because I'm hooked into the system where they can react very quickly; better because I'm being closely monitored and supported through these last days; better because I can ask questions and learn about the care of pre-term babies (because my son will be born by 36 weeks to offset other risks). I feel the same in that my pain level is about the same; the same because I continue to educate health professionals; the same because my diabetes is still fairly out of control; the same because I sit everyday, waiting for new developments, for something to change.

So why am I annoyed? Well, this (no doubt well-meaning) doctor is convinced that I should go home. His rationale is simple. My 'numbers' merit it. My trigs are lowered, my pain level is 'manageable', my sugars are sort-of-

controlled. These are all quantitative measures. Therefore, I can go home and manage from home. Though he admits that the decision is ultimately my doctor's (who has already elected to keep me admitted for all of the reasons outlined in the preceding paragraph), he insists on coming in and telling me that he thinks I can go home. He completely lacks context, and he shows utterly no interest in gaining any. In fact, at the earliest sign of debate, or attempt to explain my rationale, he heads for the door. He doesn't realise that, given my room's position adjacent to the nurse's station, I've overheard him talking about my 'case' and why I should go home; I've also overheard the nurses tell him, in no uncertain terms, that I should *not* go home, for a whole host of factors he's been unaware of – those things I try to tell him, but he doesn't care to hear. I don't want to go home. I want to stay here until my baby is born safely, and stable, until my body is sufficiently well to take the stress of a new life. I am scared, and I don't want to be left to my own devices in these last days.

(Sigh, puts paper down)

The narrator pulls off her gown, and pulls off her IV, and once again makes her way over SR as the lights come up, to the 'house' setting. There is another bassinette in the area, and toddler toys scattered about. The stack of books around the chairs is getting larger. She rifles around and pulls out the sign:

scene ix June 2008 – May 2009: Mommy OT and Contraband

She straightens, picks up toys, sits down, gets up, etc., as she tells the next story.

My second son was born at 35.5 weeks, 6 lbs. 8 oz., healthy, with congenital torticollis. That's just the medical name for wryneck, though you probably don't even know what that is (I didn't, either, till I Googled it). Your grandmother probably does, though. Medical thinking on this matter points to 'intrauterine malposition' as the culprit. Given that Noah preferred to lie transversely (width-wise, rather than the standard up-and-down position), I'm guessing that's probably what did it. Still don't know what that is? It's the condition where your muscles have tightened on one side of your neck, and as a result your head pulls in that direction, while your chin tilts towards the other. (*demonstrates for audience*) Of course, I didn't know any of this myself until my doctor pointed it out, and the minute I went back and looked at all of my little one's pictures, I saw it: the characteristic tilt of the head in every single picture. I still wonder how I missed it, but miss it I did.

Because babies' heads are still forming after birth, they are susceptible to forces that would misshape them. If the child is always putting pressure on one side of the head, then the force will cause the bones to fuse in a less-than-ideal head shape. There are different names for this, depending upon whether it's the side or the back, but in our case it was the right side, and the name, I'm told, is plagiocephaly. In any event, left untreated it will amount to a lumpy, misshapen head, something definitely not sought after in our society. Further, I was informed that, if you go about in your formative years not facing the world head-on due to the inequalities in eye and ear level plagiocephaly wrought, you run into developmental problems around balance, coordination and perception. Who knew? Actually, I did a bit more reading about this, and there isn't complete medical consensus on this: some studies point towards there being a correlation between

plagiocephaly and later learning problems, and other (some say more complete) studies don't find the same correlation. I say, Why risk it?

The first strategy employed to circumvent this outcome (and its potential long-term complications) is passive stretching of the shortened or tightened sternocleidomastoid muscle. So, you lie your baby down, and gently stretch the muscle by slowly turning his head in the opposite direction. (*demonstrating again*) And he screams. He produces such a bloodcurdling scream that you would think that you were torturing him, perhaps pulling his head off. He emits such a primal, offended scream, that his father and grandmother leave the room, and later accost you with questions such as, "Are you sure that's what you're supposed to be doing?"

After several weeks of this, the 'situation' is reassessed. If the level of plagiocephaly isn't diminishing, you move to the next stage, which is benignly called a 'cranial remoulding orthosis'. A helmet. The purpose is to provide contact to the sides that are malformed, and leave space on the opposite side for the head to 'grow'. This is where we found ourselves at about the eight-month mark. We had been working on the 'stretching' for about six months at this point in time, with no great improvement, so we (meaning Noah and I) were scheduled for a 'scan' and a fitting in December of 2009.

Now, I say that we had been doing this stretching for six months: I had no reason to think this was out of the ordinary. There is no protocol, at least readily accessible to the layperson, that provides timelines, and the default position that most of us take is that the system takes time, and that it's going to be fine (because, if it were more important, wouldn't you get a call sooner?). And much of the time, despite our gripes, we accept this (and it turns out to be true).

Why do I bring this up? Well, when we finally got our call for re-assessment, we presented ourselves at the Children's Hospital at the appointed time. We were seen by a resident, who led us through an assessment which required rating Noah's level of 'misshapeness' on 3-point scale, across 5 parameters. This would give us a number out of 15. The closer to 15 the child scores, the more symmetrical the child's head, ears and face, and the more 'normal' his or her overall appearance. They tell you this alongside the caveat that no one gets a perfect score. I watched with a sickening nervousness, because I wanted a perfect score (I always do), and I knew I wasn't coming close to getting one. The doctor viewed Noah's head from above, behind, looked at the level of his eyes, the placement of his ears, the shape of his face, hemming and hawing throughout. It was about the time that she got to his face shape that she showed her hand. In rough terms, she remarked with some surprise that, given his level of asymmetry, it was barely noticeable on his face. In fact, she said with awe, he "actually looked normal". No mother cares to hear that. His score: 10 out of 15. Her sense was that we could hope for a 13, with proper treatment. She excused herself to go share her preliminary assessment with her attending, our 'official' doctor. The specialist came in, confirmed the results, and excused herself.

Medical professionals frequently forget to shut doors, as I've already pointed out, and often commit the very human error of speaking too loudly, especially when furious. On this day, both things occurred, and the result was that I heard 'the rest of the story'. Our specialist was livid: she was incensed because, it seems, we should have been seen some four months prior, and our paperwork had been 'lost' in the system. The result was that Noah was four months behind in treatment, and that drastically affected his prognosis. I never did see to whom she was speaking, and she never did tell us the truth of the

situation: when she returned, it was with the aura of an unruffled professional, and I said nothing. What *could* be said at that point?

I'm haunted by the knowledge that my baby should have been seen and treated months earlier, and that I didn't know. He will forever bear the mark, in the form of a misshapen head and asymmetrical face, however negligibly, of his mother's lack of knowledge.

To return to the story-at-hand, and the imminent 'scan' that is used to create the headpiece: Interestingly, this story overlaps with a December 2009 pancreatic attack and hospitalisation. On December 8th Noah was to go to his first dental appointment, and on the 9th he was to arrive at the Children's Hospital for his scan. I made it to the dentist, where I proceeded to develop pancreatitis. I did not make it to the head scan appointment. For that I had to coach my husband, despite my newly hospitalised and morphine-laden brain, in the hours leading up to the appointment.

He reported the next night that it went as well as could be expected. After all, the 8-month-old was required to stay still for 20 seconds while the scan was completed. The accuracy of the scan was important: the helmet would be created from the scan. Have you ever tried to still an infant for 20 seconds? A wide-awake, agitated infant? Not that easy to do. Apparently there were soothers, keys, and other diversionary tactics employed, and even at that it took 20 minutes to get 20 seconds.

After my release a week on, I had to take Noah for the 'fitting'. The occupational therapist that we were to see had the personality of a twig. What harsh fate placed her in a position to deal with children daily is beyond me: needless to say, we were neither

welcomed nor comfortable during our time with her, what with her lack of facial expression and monosyllabic grunts that, I suppose, were meant to pass as communication.

Noah and I were taught how to put on his helmet (which honestly looked like a crash helmet), and how to put on his ‘sock’ underneath. The sock was the same gauzy material that is used in casting, and I was instructed to purchase a 20-foot length, cut it off in five-inch lengths, complete with ear-holes, to put under his helmet. This was to minimise chafing, and also absorb the sweat. I was to take the helmet off once a day, in order to wash his hair, wipe out the helmet with rubbing alcohol, let both air-dry, and place it back on. Noah was not fond of any element of this procedure, and let me know in no uncertain terms. Given his penchant to sweat at the slightest provocation, he spent all but about half an hour a day drenched within that device.

Periodic check-ups over the next several months showed some progress with his ‘re-shaping’. I was never sure, though, whether the staff in the department appreciated his camouflage-coloured helmet with the skateboarding stickers on it. Blazoned across the front was a sticker that said ‘Contraband’. The joke here was that the hospital staff took umbrage to our use of the term ‘helmet’: while in every discernible way it was a helmet, the appropriate term was ‘band’, something which they were very quick to correct us on, repeatedly. So I thought ‘*Contra-band*’ was an excellent play on this word and concept. They may not have felt the same.

That year, Noah’s Christmas pictures, birthday pictures, Easter pictures, and so forth, feature him in this god-awful helmet. He very quickly learned that, thanks to this device, he was largely impervious to the natural crashes of a toddler. He became quite fearless, and it wasn’t until he was done wearing it that he discovered that, yes, the

hardwood floor was actually hard. He eventually achieved his 13 out of 15 score after six months: now and forever he has asymmetry that I see daily (though most others don't) that will remind me of what I didn't know.

Gets up from chairs, shuffles books aside, and walks to CS, where the bright lights of 'Health Clinic' are pooled. A sign drops down from the ceiling:

scene x March 2009: Pox Parties & Vaccination Wars

The narrator watches the sign as it goes back up in the fly loft. She steps forward, as she begins the next section.

I walk into the health clinic elevator, my four-year-old in tow. We've just finished our 4½-year vaccinations (as recommended by our Province's health care system), and we're heading home. In the same elevator, another mother with a year-old infant in a car carrier, ride. My son greets the baby, and I say to the mother, "Oh, are you here for vaccinations? We've just finished. What fun". She looks at me, and scathingly replies: "We don't believe in vaccinations." Oh.

Shortly after this, we visit our chiropractor for an adjustment, and the topic of vaccination comes up (brought up by him, not me). I know better than to accept the bait. He launches into a condemnation of immunisation, about immune function and vaccinations, how vaccines effectively suppress the body's immune system and circumvents the creation (naturally) of antibodies. Or something like that. I try to keep up, but the swirl of information is too much. He even drew pictures. But I don't understand them. I do gather, though, that vaccinations are bad, holistic health care is good. Despite his impassioned rhetoric, I am hesitant to jump on the bandwagon (it's a little late, anyways – I've already had Jack vaccinated): I've used chiropractic care for 30 years since a series

of falls and recurrent headaches, and my children have been seeing the chiropractor their entire lives, but I am not convinced that chiropractic offers effective treatment for many things. And that includes infectious diseases.

Around this time, on an Internet group for parents of preschoolers intending to homeschool, there goes out a call for a Pox Party. My first thought is, “Pox? Huh?” The only poxes I know about are smallpox and chickenpox – and this *can't* be the same thing. Why would someone go *looking* for an infectious disease?? Oh, but there I am wrong: it *is* about chicken pox. This parent wants to either a) hold a play date for her children with a child that has an active chickenpox infection (with weeping sores), or b) get a freshly soiled T-shirt from the child with the weeping vesicles so that her child can, I don't know, cuddle it? Sleep with it?

I was nothing short of horrified. In my mind, this was tantamount to parental negligence. No, not simply negligence – that implied simply *ignoring* something. This was worse, far worse – it was *complicit*. It was *intentional infection of your child*. Despite my recent chiropractic lecture, I was by no means a convert. I'd read *Plagues, Pox and Pestilence* (Kiple, 1999). I knew what unchecked infectious diseases could do.

Of course, the anti-vaccinationist parents were arguing the same to me: immunisations were equivalent to complicit infection of your child, but *with unnatural substances*, hence the ethical and moral difference with the T-shirt scenario, apparently. I was still flabbergasted: given what I already knew (even from a layperson's perspective) about what unchecked infectious diseases had done in the 20th century alone, I could not comprehend how someone would *choose* to chance such a fate. I was given an answer for that, too: I had fallen victim to the techno-industrial-capitalist-pharmaceutical regime that

had infiltrated our governments, and our doctors were both complicit with and oblivious to the giant mind-game that logical positivism had played with all of us (primarily for the Almighty Dollar). This was certainly more than I had bargained for when I tried to make polite conversation in the elevator.

Steps “off” elevator, and onto the apron, and walks into the ‘night’ of her home. A stagehand brings her the sign, which she holds briefly, and hands back to the stagehand, who leaves.

scene xi October 2009 – November 2009: To the Edge of Sanity

It is late at night. She addresses the audience directly. She is sombre.

Do you know what influenza really is? No, not ‘the flu’, but real, honest-to-god influenza? I had never seen it, but I’d certainly read about it. In 1918, as pandemic Spanish influenza spread through the Atlantic port cities, in the US, officials in the Northeast sent a message to the West: “Hunt up your wood-workers and set them to making coffins. Then take your street laborers and set them to digging graves” (Iezzoni, 1999, p. 18). By the end of 1918, they’d run out of both coffins and gravediggers. In September 1918, about 12,000 Americans had died of influenza; by October, the number was 195,000. Seventeen weeks in duration, the US epidemic took 670,000 lives (p. 17). Estimates for Canada are 30,000-50,000 fatalities due to pandemic influenza during the same period (Public Health Agency of Canada, 2006, p. 3). Global estimates of the 1918-1919 mortality due to this pandemic sit at ~ 50 million people (Taubenberger & Morens, 2006, p. 15).

I’d also had a very vivid picture of the death it brought painted for me. Historian Alfred Crosby wrote:

Spanish influenza was a flu out of some sort of horror story. [It] turned people the color of wet ashes, drowned them in the fluids of their own bodies, and inspired names like the ‘purple death’. (Epidemic and peace, 1918, quoted in Iezzoni, 1999, p. 16)

Film documentarian Lynette Iezzoni elaborated further:

One moment a person was fine, the next incapacitated, delirious, dying. Wrenching coughs produced pints of greenish sputum. Blood gushed from the nose. Body temperature soared to 104 or 105 degrees. Oxygen-starved skin turned blue, purple, or deep mahogany brown. Massive pneumonia set in. In the end, patients literally drowned in their bloody, fluid-filled lungs. It was a savage, swift, terrifying death. And Spanish influenza tended to kill exactly the people the flu usually spared. The highest number of deaths occurred among people between fifteen and forty years of age, robust young people in the prime of life. (1999, p. 16)

The Spanish influenza was a strain of H₁N₁, and its deadliness was not attributable to an aberration that will never recur: far from it. Researchers have been tracking and modelling influenza outbreaks around the world for years now, and the consensus is that it’s not a matter of *if*, but *when*. Current estimates of the mortality rates with the next global pandemic range from ~20 - ~500 per 100,000, conservatively (Simonsen, Olson, Viboud, Heiman, Taylor, Miller & Reichert, 2005, p. 90). A little simple math gives us a death toll of anywhere from 1.4 to 36 *million* people. “Oh,” you might say, “That’s still less than 1918,” as if that were some kind of consolation. Remember, these numbers are *estimates*, and they factor in our era’s ability to manufacture and administer vaccinations, communicate swiftly across the globe, and manage many of the symptoms formerly

considered unequivocally deadly. Even with all of this, the death toll is *still* enormous. With global population growing by *millions* each year, it isn't difficult to see where such a pandemic's implications are more than any of us can possibly fathom.

I'm sharing all of this information as context for the story I'm about to tell you next: I want you to have a very clear picture of what it is I am talking about, what I ostensibly knew going into the event, and the reason I call this scene "To the Edge of Sanity".

In September 2009 came the initial flurry of reports that a pandemic, first called 'swine flu', then H₁N₁, was headed to Canada, and that precautionary measures, primarily in the form of an H₁N₁ vaccine, were to be taken. The message from the government of Alberta was clear: every eligible person was to take advantage of this prophylactic action, and the government was doing everything possible to enable such. Somewhat impotently, there were only four clinics established for Calgary, a city of over a million people, in the last week of October 2009. As the immunisation effort launched, media channels were immediately saturated with stories of line-ups that took six to eight hours, in the biting October cold, and reports that clinics were running out of vaccine stock. Within days, more stock arrived, new clinics were established, and a priority list of vaccination recipients was implemented. Young children, their caregivers, the elderly, and emergency personnel topped the list. Calgarians were much relieved to find out that their NHL hockey team also received private, and priority, immunisation. The media firestorm and public outrage of this particular instance of 'urgency' were impressive (Bennett, 2013).

As a mother of two young boys, I was on the 'priority' list. At my son's preschool the curbside debate raged amongst the mothers: Are you getting your kids vaccinated? Do

you think we should get vaccinated? Do you think there really is a pandemic coming? Do you think they even know what the pandemic strain is? Does this vaccine offer any protection whatsoever against the strain? I listened with interest, then fear, then panic. I didn't weigh in. There was so much "information" being "shared", the aura of judgment was unmistakable. I decided there was nothing worse than mothers judging mothers – a more vicious breed of human being does not exist.

During all of this, a maelstrom of debate around vaccinations – flu, H₁N₁, the connection between the American Medical Association's schedule of vaccinations and autism, the efficacy of paediatric immunisations, herd immunity, and so forth, raged around me. Governments were broadcasting widely, as were medical associations, alternative health associations, political groups, and laypeople: everyone had an opinion. I could not turn on the radio, the television, read the paper, or visit a website, without being inundated with 'evidence' about vaccines. I want to scream: I wanted to do the right thing for my children, but **what was the right thing?** In this whirlwind, I lost sight of what I did, in fact, know about influenza (the H₁N₁ variant), which was arguably more than the average parent. I knew it was swift, horrible, deadly, picked off the young and able-bodied, and highly contagious. And I hesitated.

Fate decided for us. On October 29th, my oldest son (then just four) came down with all of the hallmarks of H₁N₁: coughing, fever, pallor, difficulty breathing. Earlier in the week his father had shown the same symptoms (but much more mildly), and had insisted on going to work (where he undoubtedly picked up the germ from someone else who insisted on going to work), and now our child was infected with *something*. Just a few days prior, the province had shut down broad testing for H₁N₁ (due to system overload),

and only offered it in cases where urgent care and hospitalisation were involved. The doctor we saw at the walk-in clinic made his diagnosis based on ‘if it looks like a horse, and walks like a horse, then...’. Our son was not ‘urgent’, by the Health Region’s definition, which was governed almost entirely by the availability of beds in the hospital (a fact I know from numerous 30+ hour stays in the back halls, converted storage rooms, and modified waiting room snack areas of hospitals, waiting for a bed to open up). Notoriously underfunded, understaffed, and bed-deprived in the general public’s estimation, our Health Region lacked the capacity to deal with the onslaught of cases provisionally diagnosed. Interestingly, our health system in Canada and Alberta is considered to be one of the best in the world, and I would say I’ve seen fair evidence of this from time to time (Health Quality Council of Alberta [HQCA], 2013). However, it does beg the question: if this is (among) the best, what must others, in other countries, economies, and levels of development, contend with, especially in instances of pandemic crisis? It’s terrifying, really. Regardless, as my son wasn’t “sick enough” we were sent home to manage this health crisis on our own.

The next few days were awful. Trying to nurse my son, without support and without clear answers, was nightmarish. The coughing, the fevers, the pallor, the lethargy, whether H₁N₁ or not, are hard to describe: and *if* he had influenza (I will never know: I only know that he survived) and *if* it was ‘milder’ (given the fact he was never hospitalised) than the full-bore infection, then we should all be terrified.

Watching the media, it seemed clear that vaccinating hadn’t provided people with clear immunity (though decreased impact of the disease was speculated), and other quarantine measures hadn’t amounted to much (not because of conceptual inadequacy:

rather, due to human fallibility). I feared for what might happen next. In the absence of definitive diagnosis, my son's preschool had allowed children to attend who were obviously ill. Despite the Public Health Act, and despite protocols from Alberta Health Services around outbreak identification and management, children were still being permitted to attend. Dare I speculate, in the case of this private institution, that dollars trumped decency? Because a *confirmed diagnosis* was seen as the benchmark, and only hospitalised (and thus non-attending) children could get the testing, and also because many parents were faced with the dilemma of having to ask for time off to nurse a sick child (and were they *really* sick? how 'really' sick?), ill individuals were knowingly put into the school system (and, frankly, into the workforce).

Skip ahead two months: Jack has been sick for weeks, and just as we finish one illness, another emerges hard and fast. I've done everything 'right' (*after*, of course, failing to immunise), followed the antibiotic dosage instructions religiously, sanitised everything, reduced or eliminated exposure to viruses and bacteria, changed everything possible in our household to toxin-free, yet it doesn't help. I'm exhausted, and he is looking terrible. He has dropped from being a vibrant 75th percentile little boy (height/weight), to 9th percentile in his weight. Every possible nightmarish scenario I can imagine has played through my head. I insist on blood tests. My fear: leukemia.

Soon it's determined that my son has some sort of immune deficiency, and we were referred to the Children's Hospital to see a specialist. At first, all we know is that he tests low (meaning outside the 'normal' range) for IgG (immunoglobulin G), and that this is probably why he's gotten sick, and stayed sick – an H₁N₁-like illness, a malicious stomach flu, five ear infections (with two perforated eardrums), scarlet fever. He'd gone from a kid

that had been on antibiotics once (as a prophylactic when exposed to whooping cough at two years old), to a kid that was on them (five different courses, three different types) for almost four months straight.

Once we make it through the referral system to a paediatric haematologist, one of the first questions we're asked during our two-hour assessment is whether his immunisations are up-to-date. I answer that they are. In fact, he has met his immunisation requirements to the day: at 2 months, 4 months, 6 months, 18 months, and 4 ½ years, as per the Alberta Health Services standards. The specialists (again, a fellow and an attending) nod and smile and make notes in charts. I try to ask about the potential connection between immune deficiencies and vaccinations, and the question is quickly dismissed with a half-laugh. I'm encouraged by the physicians to make sure that my son gets a flu vaccination when the season approaches again. A tentative diagnosis is made – transient hypogammaglobulinemia – and we are told we will be scheduled to return in six months, which turns out to be ten.

In terms of his diagnosis, we're told the 'transient' refers to speculation that it's maturity-related, and he will 'grow out of' his substandard IgG levels (the 'hypo' in hypogammaglobulemia), which is to say, his natural immune function was not operating commensurate with his age – as children mature, they develop stronger immune systems, typically.

When asked, in retrospect, whether I'll vaccinate my children in the future, I still cannot give an answer. In many ways, a leap of faith is required - both to vaccinate, and to *not* vaccinate. As I stand in here in 2010, I have more questions than answers, and I don't like this feeling.

Now the narrator moves back to the 'living room'. Stack of newspapers are about, the radio plays in the background, and the computer is open. She is reading and searching slightly manically. The sign drops from the fly loft, and she doesn't even look up.

The narrator stands and moves to the apron: however, this time she not only uses the CS area. As the narrative progresses, she moves about – perhaps she even moves into the audience's space. The feeling of constant movement is important – it isn't frantic, only very busy. The stage now holds random stacks of books, which she moves around as she speaks. She grabs the sign as she's moving, depositing it elsewhere on the stage:

scene xii February 2010: Multi-tasking Mommy

And begins this twelfth story, delivered in a more manic tone and style than previous episodes.

Today began at 6 am. As I woke, I remembered that today my younger son had a specialist appointment with the dermatologist. Then I remembered the forecast. I leapt out of bed, peeked through the curtains, swore, and then ran for the shower. The 8:50 am appointment was in the core of our city, about 25 km from our home. I would be sharing the whiteout roads with thousands of people. And two small children, in an enclosed space.

I rushed to ready myself and get each of the children up and dressed. We pulled out of the driveway at about 6:50 am. What then ensued was one of those painful, hypnotic drives that are the special hell of blizzarding pre-dawn February hours in Alberta. We chatted for a while, but the roads continued to worsen, as did the traffic (when your almost-three-year-old says “mommy in traffic?” you know things can't be good). I flipped down

the DVD screen, and watched the minutes pass: one hour and forty minutes later, we arrived.

I swaddled the children back into their winter clothes, and hoisted them from the vehicle, aggravating an already-unfortunate prolapse situation (more on that later), and we wended our way through the rabbit-path to the door. For a brief moment, given the absence of footprints at the entrance to the swish clinic, I feared that it hadn't opened in the snowstorm. Had that been the case, it would have resulted in a spectacular temper tantrum, hosted by mommy, for all the passers-by on 11th Avenue. Happily, we were greeted with an empty waiting room, and a clerk that congratulated us on showing up on time, and at all.

The doctor was able to see us very shortly after we arrived (thus proving the adage “the early bird gets the worm”, though I'm not sure who the worm is here), and he welcomed us like long-lost friends. This physician, in many ways, defies the stereotype of the specialist, in that he engages in friendly conversation and gives every impression of *caring*. It might be an act, but by god – it's a good one. I begin to explain my son's situation, and he cuts me off with, “You don't have to explain: the story is all there in his skin”. He goes on to explain my son has eczema (which I already knew), and that he would have it his entire life. Apparently, there is a particular gene that controls the production of filaggrin, a protein that is supposed to be present in abundance in the outermost layers of skin. In the doctor's explanation, the filaggrin makes the skin ‘tight’, but in those lacking the necessary amount, the skin is ‘leaky’, allowing antigens in, and causing swelling and redness. As well, the scarcity of filaggrin leads to the flaking skin associated with eczema. This ‘leakiness’ exposes the interior to antigens that can

essentially prime the immune system to ‘react’ further at a later time, in the order of eczema (check!), asthma, allergies, and then hay fever.

Well, this was news. The doctor then looked at *me* and stated: “Well, we know where he gets it from”, implying that my red hair and fair skin might be an indicator of shared genetic tendency. He’s right, of course, but I have no recollection of skin troubles as a child, and I even called my mother later to confirm my memories (I did find out, however, that my father, and his father, were similar genetic victims). The doctor went on to assure me that it wasn’t food or laundry related (not causally at least, but perhaps they could aggravate the situation *more*). This started my wondering if there were things that I could do that would aggravate his condition *less*.

We left with instructions on how to use our prescription, as well as home care (involving unscented Dove soap and vast amounts of Vaseline creamy lotion) as well as the reassurance that this was not the result of bad parenting. While it was certainly comforting to hear this, truthfully I had never even thought that a possibility. I’m the first to accuse myself of bad parenting on many an occasion – this just wasn’t one of those occasions. I didn’t know about the gene situation, I’ll admit, and I didn’t know about the ‘priming’ for future reactions bit, but I knew what eczema was, and how – basically – to treat it. And when that rope ran out, I sought professional help.

What’s really interesting, I think, is my thought process as we were finishing the appointment, at about the point he was outlining the home treatment guidelines. I will warn you that what follows here is ridiculous. I *know* this. Do you know what I thought about when he first recommended Vaseline? I thought “petrochemicals”. I didn’t even ask myself at the time *why* I thought that. And when he said it was cheap, I thought, “I don’t

care”. I also didn’t question the potential meaning(s) of that reaction, though I freely admit that it is, at minimum, arrogant.

I started the drive home, thinking through the array of organic soaps and lotions we had at home, and I kept coming back to the double-edged sword: “Will use of the prescription, plus the barrier-creating and –protecting abilities of the organic products, be enough? Or do I have to bow to the other option, to ensure my son’s dermal-wellbeing?” This caused a fair bit of drive-home grief. I was truly conflicted and torn. Over lotion.

A sign drops down over CS, as the narrator continues to walk and talk. After a while, the sign slowly retreats, unacknowledged.

scene xiii February 2010, Continued: A Trip to the Grocers

My next stop that day, after dropping my kids at dayhome, was the market. I subscribe to the belief that what we eat is pivotal to our overall health. Initially, I held that principle in an abstract “saying the right thing” sort of way. However, after my initial go-round with pancreatitis, and especially after my son became ill, that belief became creed. On this particular day, I chose a market that had a growing assortment of organic products (maybe 1% of its product mix, versus perhaps .1% a few years ago), and a fair selection of locally-grown items, and set to work. Up and down the aisles I went, scanning for my items. First stop: Produce.

Now, the produce section of my market is perhaps five feet wide by twelve feet long. The mix is pretty standard: apples, broccoli, avocados, kiwi, potatoes, onions, carrots, grapefruit, celery, kale, mushrooms, pears. Occasionally a pineapple shows up for the party, but not often. So here I am, trying to buy food, and I am going slightly insane trying to make my choices: yes, I want to buy fruits and vegetables for my family that are

as pesticide-, herbicide- and petrochemical fertilizer-free as possible (hence the ‘organic’), but at the same time, I am painfully aware of how far those dastardly little kiwis have had to travel to make it to my frozen prairie produce section (New Zealand, anyone?). The same can be said for my apples, broccoli, grapefruit, and so forth. Pretty much the only locally- and organically-grown choices I have in February are potatoes, onions, carrots and winter squash – the ‘root cellar’ crew. Peruse any prairie cookbook from a hundred years ago, or read “Little House on the Prairie” and you’ll see that this is not a new situation. What am I to do?

Before leaving the produce section, I commit at least three organic and/or 100 mile diet sins that I am aware of: I choose pallid non-organic tomatoes from Mexico (which, of course, given their cardboard taste, begs the question of ‘why bother?’), hydroponic cucumbers from British Columbia, and utterly depraved non-organic nectarines from *Chile*. That’s over 10 000 kilometres from Calgary. I feel slightly ill, but I know this is a far better compromise than letting my husband loose in the produce section, bring home all manner of iniquitous fruits and vegetables, tempting our children like the Pied Piper, and letting them believe that Alberta produces a veritable cornucopia in February.

The rest of the trip through the market consists of varying degrees of moral angst: I buy a pizza kit for the weekend. I love those things. They’ve been around since I was a child, and it was an exciting day when mom whipped out the Kraft pizza kit. I know, I know: not organic, not local, not even particularly healthy. I even tried to look up the nutritional breakdown as I was writing this later in the day (mostly as a way to avoid going to the kitchen to actually get the box), and kraftcanada.com does not list the ingredients. Interestingly, however, they do have extensive side panels for the following headings

(under their dropdown menu heading ‘Health Living’): healthy weight, body mass index, calorie burner, daily planner, Canada’s food guide, physical activity guide, diabetes centre, basic nutrition, calcium 101, kids’ nutrition, family fitness, allergies and ‘all about antioxidants’. Truthfully, I would never have thought of Kraft as my ‘go-to’ place for healthy lifestyle information.

I have to ask: How on earth did I get here? How come I can’t just listen to the doctor and buy some freakin’ cream for my son? Why does the trip to the grocery store have to be an exercise in thesis-quality internal dialogue? Why do I feel stressed out before noon over a pizza kit? What has changed so much that I now can’t go through my day without obsessing over the details of the when, the why, the what, the who?

The narrator finishes her manic movement from the preceding sections and ends in the area SL, the ‘medical’ area. Her books piles have again grown larger. She has to dig around a bit to find the next sign, which reads:

scene xiv May 2011: The Prolapse Files

She ‘files’ it elsewhere, puts on her hospital gown, and begins.

So, after all the food and lotion drama, I had another event penned into my social calendar: prolapse repair surgery. Ever heard of it? A prolapse occurs when your insides try to become your outsides. It happens to around 50% of women after childbirth, it turns out. It starts as discomfort and graduates to painful, and can eventual become unliveable. I was fast approaching this latter stage at the time of my assessment appointment.

Did you know that there are four *levels* of bladder (cystocele) prolapse? Neither did I. Mind you, I didn’t know that there were four *types* of prolapse, either, not until I

went for assessment after my second son was born – like *three years* after. Turns out I had 3 out of 4 types. That’s like a 75% success rate, isn’t it?

Without going in the gory details (believe me: you *really* don’t want me to), three days after this unpleasant surgery I was prepped for release. This process sounds simple enough: the nurse gives you some paperwork, you go over it, the nurse does the final charting, the doctor shows up and signs off on it. Except that this can be an epic waiting game, a cat and mouse marathon of the nurse finding time to chart, the doctor showing up on the unit, the two of them actually speaking to one another and completing the paperwork, and you getting out the door.

This time, however, I was informed there was a new protocol: I was to be *read* the sheet by the LPN (Licensed Practical Nurse) assigned to my case. I protested that I was more than capable of reading my own material. The nurse informed me that this was “the way it was”, and so the LPN came and sat beside me, and commenced to read. Or rather, attempted to read.

This particular LPN (whom I’d met earlier in my stay), though kind and considerate, was only marginally fluent in spoken English, and even less so when tasked with reading English aloud. Even ‘plain language’, the form of choice for patient handouts (though they are still, and always, replete with specialised terminology) was a stretch. So there I sat, trying to listen patiently to her massacre the reading, one that I was done by the time she rounded off the first section. Assuming that interpersonal communication efficacy is part of the competency profile for an LPN, this moment was not an exemplar.

The narrator holds up a piece of paper, and continues:

While I don't understand the internal politics that led to this woman being in this position beside me, and assuming there was some sort of 'on-the-job' training taking place, I ask you: if you're learning to speak aloud a language, would you want to face this title -- "Discharge Instructions for Bladder Control Surgery: Tension-Free Vaginal Tape and Trans-Obturator Tape"? Or "If you are prone to constipation, it is important to eat foods high in fibre, such as whole grain breads and cereals, and fruits and vegetables. **Using a stool softener may be helpful**"? (Calgary Health Region, 2005) That last bit was in bold. It's not that the *words*, per se, were difficult – but, given the topic, the inflections, pausing, phrasing, or pronunciation can make or break the comfort level of most anyone, including the reader.

Her situation was one of 'trial by fire'. To make matters worse, the nurses all knew that I was working on my thesis because, in addition to my suitcase, I'd brought my laptop and two crates of books to the hospital. It had been openly discussed. This was *not* your normal medical release encounter, on pretty much any level.

So, here now sits this poor person next to me. She is horribly uncomfortable, and her embarrassment is unmistakable. She is stumbling through the pronunciation, the phrasing, the inflections – and if I was truly in need of having this read to me for understanding, it would have been an unequivocal failure. Her supervisor was nowhere to be found during this experience, and there was no one and nothing to help her navigate this treacherous and degrading terrain. If this was 'on-the-job training', there wasn't much 'training' happening. There was little hope of improvement or understanding for anyone in this exceptionally awkward situation.

So I crossed the line: I began tutoring her (and, for the record, had it been a 'him', I would have done the same). I modelled the pronunciation, the inflections and the phrasing that was necessary for the document. What would have happened had this person's supervisor walked through the door while this was occurring? I can't imagine a situation in which the supervisor would have been happy. Had I put this international LPN in professional danger, because I was more literate (at least from a communicative standpoint, though perhaps not more *health* literate) in this particular situation? Where must the responsibility lie in such matters? Would it have been better to let the LPN flounder, not learning anything, and then move on to the next patient encounter, feeling equally overwhelmed? Should I have complained to someone? Should have I complained about the supervisor? Wouldn't that have risked repercussions for the LPN? How does anything in this encounter enhance *my* health literacy or compliance? Or was it merely a legal exercise in making sure the patient had the release information presented to them (however poorly)? Power, communication, health, all wrapped up in one complicated little bundle.

The narrator takes off her hospital gown, grabs her bag and walks back to the middle of the stage. The sign drops down:

scene xv June 2011: Back for More

She then heads straight back to the hospital bed, and puts back on the gown. She goes to lie down, on the bed, and half-way down, pauses, thinks better of it, and gets back up. She stands, thinks for a few minutes, and then she takes off the gown, drops it on the bed, and walks out. She marches across the stage to the 'house', where the lights show that it is early morning. She speaks.

Today I was very non-compliant. At 5:20 am, Monday morning, I checked myself out of the hospital. I happily signed the ‘leaving against doctor’s advice’ form, and the nurse phoned the resident to tell her to take me off the surgical list for the day. The resident offered to come “discuss the matter with me”, presumably to talk me off my insensible ledge. I declined. I was given a wheelchair to cart my belongings to the main entrance, and there – to my surprise - I found cabs waiting for fares *from* the hospital (at 6 am on Mondays?). By 6:20 am I was standing in front of my husband. He just about jumped out of his skin – I was supposed to be in surgical recovery, not standing in our bedroom. I think he may have thought I died, and he was getting a ghostly visitation, though I don’t think he’ll ever admit that.

I just stood there. What could I say to my husband, who has been just this side of a saint through everything in the past half-decade? Through all my medical trials, he has had to continue working, picking up the slack, coordinating schedules, bringing the kids to grandparents or the hospital, and stay healthy and sane himself. It simply was not fair. I told the truth, or at least my truth: I think I have finally hit the wall. It’s been five years since I was admitted for my first ‘diagnosed’ pancreatic attack and my diagnosis of familial hypertriglyceridemia. And on June 1st, 2011, just 2 weeks after my prolapse repair surgery, I was admitted again.

So, as I stood there that morning, I told my husband: This has to be the last time. I have no more in me. I am done with this.

More than anything, I was pissed off: at myself, and at the world. I knew this was coming – it was merely a matter of time given the preceding six months (stress elevates my triglycerides, with or without medication). I had taken action a few days earlier, asking my

physician for a letter that would enable me to take time off from my doctoral program (it's the only thing I can 'take off' – being a mother doesn't have a sick days clause), but it was too little too late. I should have done it sooner, but I didn't want to let anyone down.

This time was different, though: most times there is a dance that spins around things like amylase and lipase levels and pain management and “how bad is bad”, but in the past I have never had a single hospital person, specialist or otherwise, question the specialists' diagnosis of my triglyceride ‘problem’. This time, the internist came by and informed me that I didn't have pancreatitis – I had a ‘sludgy gallbladder’ that necessitated its removal. When I asked him about all of the tests and symptoms that matched *every other hospitalisation*, he shrugged it off, saying, “You don't have that; it's too rare,” and continued to speak over me.

Frankly, I was too flabbergasted to advocate for myself at that moment: faced with the denigration of five years of experience, I had nothing to say. What was worse was, even when my husband tried to speak on my behalf, this surgeon ignored him as well, and said, “You can take it or leave it. It's your choice. My resident will come back to see what you've decided,” turned on heel, and departed. Informed consent, my ass.

The resident returned, informed me that, if I “just signed the papers” I could have my gallbladder removed that day, remain in my private room, use my existing IV line (a bigger deal for me than it might seem to others) and be home and better by the next day. Five years of problems solved instantly, if I was to believe this story. I had no access to a second opinion, no Internet, no books, no one to talk to: only a piece of paper and an expectant (literally and figuratively – she was about seven months pregnant) resident standing before me.

I signed. I didn't know what else to do. About twenty minutes later, the nurse showed up and informed me I was being moved out of my private room to a ward – I protested, but was told that I “was no longer an internal medicine case, but a surgical one, and they needed my bed”. I was unceremoniously dumped onto a stretcher, my belongings piled at my feet, and wheeled away.

The ward I was taken to was a very large room, with two sizable curtained enclosures on either side. There was about 40 feet between the right and left sets of ‘rooms’, and all along the back wall was a giant picture window with tables. Within each ‘room’ was a secondary enclosure, a 3-foot by 3-foot area with a toilet and sink that could be cordoned off with another curtain for ‘privacy’. Never mind that all that stood between you and the earshot of three other people, their visitors, and all manner of hospital staff, was the soundproofing afforded gauze.

Deposited in the back corner, I was told to “relax” and “try to get my bowels to move”. I would be informed of my surgical time “shortly”. Relaxing seemed unlikely. Though I was officially on the ‘surgical’ floor, apparently they had not received the same memo the medical floor had about keeping beds for those that needed them – I was the youngest in the room by about fifty years, and not a single other person there was surgical. It appeared that I had landed in the geriatric ward, much the same way my hospitalisation in 2008, at a different hospital’s internal medicine ward, had actually been a visit to the psychiatric/dementia ward, locks and all (and *no*, I was *not* a psychiatric patient. And *yes*, I am sure of that fact).

Amidst the moaning, screaming, and endless calling for the nurses (which was very like the psychiatric ward, I must admit), I was hard pressed to relax. I was also uninspired

to “move my bowels”: while I doubt that my ward-mates could actually *hear* much of anything, I was still too much of a prude to even consider the amenities my room afforded. I asked where the nearest “private” bathroom was, and about every hour and a half I’d unplug my IV and trot to the other end of the unit to the visitor’s bathroom to get rid of my latest IV fluids.

After several hours of waiting for someone to say something – or, indeed, *anything* – about my surgery, I was forced to once again journey out, this time to the nurse’s station. It turned out that my surgery had been postponed. By how much was anyone’s guess. They’d update me. The day wore on, and every 2 hours or so they’d come to tell me that it had “been pushed back again”. At 11:30 that night, the nurse came in to tell me I could have a cup of apple juice, and then I would go back on NPO at midnight, because they were now scheduling my surgery “sometime tomorrow.” I asked her if that was a sure thing, and her response was a shrugged “That’s what they told me to tell you.”

By this point, I’d been off all food and drink for three days, and my vein had blown three times. I was already seeing blood in my current IV port so I knew that there was little chance of it lasting until morning, let alone until surgery. The very thought of the process of finding yet another access site brought me to tears. One IV placement usually resulted after 4-5 attempts, complete with something called ‘fishing’. It *is* as unpleasant as you might imagine. So, already 14 tries and three IVs in, I was not keen for another go-round.

By 3 am I was lucid: the surgeon didn’t believe me or listen to me, I had no way of getting advice beyond the push to get surgery, I had lost my room, I was about to lose my IV, and heaven only knew when my surgery would be. I had signed a paper, yes; but that did not constitute informed consent, nor had I sold my soul, to the best of my knowledge.

When I asked to be released, and effectively withdraw my consent, I was regarded as slightly mad. They kept saying, “Are you sure? Do you understand??” Interestingly, no one showed similar interest when I was signing the consent papers in the first place. I was told that I “would remain in the surgeon’s queue”, and that I would likely be called in October by his office to schedule an outpatient procedure. That was in June 2011. As of November 2013, no call yet. It’s hard to believe that this is *not* punishment for going against doctor’s advice.

The light changes to a single, CS spot. She slowly makes her way into this light, and after a very serious pause, where she holds up the sign she finds on the stage’s apron, she begins.

scene xvi November 2011 – March 2012: Epiphany

I’ve been hinting at something called ‘health literacy’. I haven’t come out and whacked you on the head with it simply because it seemed so crude. I wanted you to hear stories – stories about how I have learned things, experienced things, and dealt with things related to my own health and wellness and that of my family. I wanted you to have a framework to understand the depth and the importance of the concept before you had a prescribed term or idea to attach it to.

I wanted you to consider many of the ways a person might encounter the ideas of health, health care, and ultimately ‘health literacy’, so you didn’t have just one way of conceiving of it, and while I was certainly intending to expose you to a variety of ideas, I hadn’t imagined that that the *end of life* through the end of health might be something that I took up in this work.

But, ultimately, I suppose that any pursuit of ‘health’ through ‘health literacy’ is the pursuit of something more – more ephemeral, more difficult to grasp. Why invest so much time in thinking about, talking about, learning about, managing, and so forth, health? I think it is simply because we have come to value the idea that there is an ‘optimum’ health that is both attainable and desirable, and we’ve come to expect our technology-driven medicine to provide it to us. That, and we’re afraid of death. We will do whatever it takes (in many instances) to prolong life, to intervene in the face of demise, because we will take what we know (life, however precarious that state and notion) over what we don’t know (death, and whatever, if anything, that comes afterwards). And the more that technology allows us to know, whether that’s life-saving devices, treatments or diagnoses, the more afraid we become of what we don’t know.

Health literacy, and what it ultimately advocates, is ‘knowing’. Knowing about the various systems and procedures for becoming ‘healthy’ and staying ‘healthy’ and avoiding death. Of course, our day-to-day decisions and actions aren’t so dramatic – what vitamins to take (or not), what exercise to take (or not), what food to eat (or not), what screenings to undergo (or not), what medicines to take (or not) – are all little bits of the puzzle, but none of them points (at least immediately) to survival (or not). We’re really playing a game: the more we know, the more that we can play our cards to maximise the benefit to ourselves and the more we can stretch out our time here on earth – finding the winning hand.

But this trust in, indeed this worship of, technology-driven intervention, and its ability to lengthen our stay here, is perhaps misplaced, or at least, overly weighted.

I’m certainly not advocating an abandonment of the successes technology has granted medicine. I am here, talking to you, as a direct result of a medical intervention that

saved my mother and myself, one which would not have been possible even 30 years prior to my birth. I am a success statistic, and for that I am grateful. But my mother's health literacy had absolutely nothing to do with this success: in fact, her doctor in my small town almost lost us both because of a mistake in using the available technology. My father's faith that another doctor, in a bigger, more sophisticated centre, would be able to help was the deciding factor. His conviction saved our lives, as much as those doctors in the city. He didn't have any *a priori* knowledge that he used to make the decision – only a belief that something more *must* be possible.

However, let us come back to now: now, it's my father's little sister who is ill. She has metastatic cancer. She recently collapsed, and testing has revealed multiple tumours: renal, intracranial, breast, and lung. The intracranial tumour, and the subsequent bleeding into the brain, caused the collapse, and now she has lapsed into a coma. It's unclear whether she'll regain consciousness, but even if she does, the prognosis is bleak. The tumour is such that it's inoperable, and hospice care is the recommended route. So, in a nutshell, the cancer is death-sentence, and it's merely a matter of time.

My father refuses to accept this, much as he refused to accept the doctor's diagnosis and treatment of my mother while in labour with me almost 40 years ago. But my aunt is married (and has been for my entire life) to a man that *does* accept this. And because he's the husband, the choices are his to make. My aunt had had oral cancer and ocular cancer some four years prior, and at the time she lost her eye but not – to our collective surprise – her life. In the intervening years their only child remarried and gave birth to a granddaughter (something no one expected). So, by all accounts, those four years were a blessing, one that medicine granted her. Our family is not close, and does not talk about

things of a personal nature, and so I have no way of knowing what transpired between my aunt and uncle, what sort of understanding or agreement they had should the cancer return (and they knew it would).

So when my aunt collapsed, all of these things rose up to greet us.

My father has always been very close to his sister, he being 8 ½ years older, and in his mind he has always looked out for her (or at least, that's his job description as older brother) throughout her life. The other mitigating factor is my father's belief that life should be fought for at all costs, and that technology (somewhere, somehow) can be called upon to stop or change the progression of the beast called death. You just have to know where to go, who to talk to, what to do.

In what little bit of 'free' time my father allows himself, he watches programs on and reads about medical developments. Perhaps in another life, given the opportunity, he would have been a physician – I don't know. All I know is that he holds a particular fascination with technology and medicine, and the 'miracles' that Progress allows. So when faced with the prognosis for his sister, he did what he does: he started trying to figure out how to 'fix' the problem (because that's what you do – when something is wrong or broken, you fix it). And because I'm the 'educated' one in the family, and the one who ostensibly knows her way around research, I got the phone call. This is a phone call you never want to get: when someone you love dearly is faced with the most awful of situations, and they turn to you for help. Help that you cannot give.

My father remembered watching a program 'a while ago' (1 year? 2 years? 5 years?) where researchers had used brain cancer patients' own cells to fight their cancer – successfully. He couldn't remember the facility, the researchers, or the name of the

technology or procedure – only that someone with brain cancer like my aunt (he thought) had been cured by this new medical advancement, after being given a death sentence. His request for me was to find the program, find the research, find the doctors, find the facility, and find the phone number. This was a Friday night, three nights after my aunt’s collapse.

What ensued was the most exhaustingly futile night of my life. I knew two things going into the search: first, that I was very unlikely to find the research in question (or the miracles that it purported) and second, no matter what I found, my uncle was not going to change his position. After all, at this point he was refusing to even tell my aunt the gravity of her situation. It would be very hard to cart someone to Seattle for treatments for the flu (which is what his byline was at this point, as she had finally regained consciousness) without it causing a few questions.

Nonetheless I searched. I learned about programs in Boston, Baltimore, Toronto, and Seattle, I learned about radical treatments being offered in China (for a price) and how people were using their blogs to help raise money for their own offshore treatments. I read about research undertaken in New York at Sloan-Kettering Memorial; I searched archives for old documentary footage; I ran across alternative practitioners who had been black-listed by the medical community for their radical treatment protocols, and had relocated to posh private practices in places like New Mexico and Texas. The closest I came to finding anything was research that used patient’s cells to manufacture disease-fighting products. Even that, though, didn’t seem to fit the bill, especially since the lead-up to the treatment took several weeks to produce enough cells for injection, and then the actual ‘cure’ took several more weeks, even months, to show any progress. My aunt had (at the current best guess) days. All of this I gleaned in my Internet search. And all the while I was making

decisions about where to go next, what information seemed authentic, credible, or useful. My ‘health literacy’ was alive and well that night, but I knew that I was up against something that no amount of knowledge was going to affect.

Is it preposterous for a layperson to think that they might know more, or find out more, than an expert? That the expert might not know everything, and that the layperson was within his or her rights to try and search for things that are perhaps beyond the immediate experience of the expert? Isn’t advocating health literacy in effect advocating the search for more knowledge? But how, then, does any of us know when there is no more to know, whether we’re expert or layperson? My mother-in-law perhaps put it best a few weeks ago when faced with the diagnostic circus that ensued when my father-in-law seemed to have a heart attack (but turned out to have a pulmonary embolism – and survived): “Don’t ask me any questions, I’ve told you everything I know. I’m not asking the doctor’s any more questions, because I won’t understand the answer. At some point you have to have faith that the experts know what they’re doing.”

My father, faced with the information (or lack thereof) that I provided, still felt that something should be done. One shouldn’t accept death, especially early death (she was days from her 56th birthday). This led to a stalemate. My father had no authority, and this was devastating to him. My uncle chose hospice, and when, some three months later, my aunt decided to go off her medications, she immediately (before her choice could be implemented) seized, lapsed into a coma, and died less than 24 hours later. One cannot calculate the long-term effects this series of events will have on my family, what sorts of blame will be thrown about, what sorts of accusations will be levelled.

To one side, hospice is the humane, gracious way of passing those last days of a life destined to end; to the other side, hospice is failure to act, failure to try, and ultimately failure to care. But how to know which path to take? How can something like health literacy help us to sort out when hospice is humane, and when it is a morphine-fuelled death sentence? How can it assist us in determining when one more treatment or prescription is an insult to our remaining humanity, and that letting go quietly is, in fact, the most compassionate action we can take?

Does this particular incarnation of health literacy hold out false hope? Hope that if one just searches enough, the answer can be found, that one can become informed enough to affect real change to health and wellness outcomes (even circumventing death)? Where is that tipping point where we've stretched beyond the safety of our tree limb, and we too are about to fall?

A sign drops down, and she grudgingly acknowledges it, before beginning the trip
SR.

The lights come back up in the 'house', as she makes her way back to her (ever-filling) reading room. The lights should be designed so that she can walk, and talk to the audience, without passing into shadow on the way there.

scene xvii January 2012: Coming Undone

Post-prolapse surgery (2011) I had a lot of pain. This was dismissed as 'normal post-operative pain', but it didn't feel normal. It took 10 days to have a movement, if you know what I mean, and it was apocalyptic – worse than with post-partum stitches, if you've got the basis for comparison. I repeatedly told my husband that I thought something tore, on the *inside*. I had visions of all the hitches and stitches I'd been given coming loose, and

haphazardly hanging there. The pain did, eventually, fade, after about 3 months. I didn't pursue this with my doctor, though: I'd been told to 'give it six months', barring an infection.

Fast-forward to late fall 2011. This was about the time that I noticed something unpleasant: I could bend forward to pick something (or someone) up, and when I stood up, there was a trickle down my leg. Of urine. I expect incontinence with my 90-year-old grandmother (who, incidentally, had a prolapse repair done – which failed – in the 1970s – blame the technology), not my own 37-year-old self. At first, I thought that I was imagining things, because I couldn't feel anything. Prior to my first reconstructive surgery, I could actually sense the flow of urine. Not now.

A bit more self-monitoring, and I confirmed that, yes, I was 'leaking' again. Now, amongst women of a certain age and life-circumstance, there run jokes about peeing oneself laughing. Except they aren't really jokes, and we all know it. As a rule, most people don't have deep conversations about these things with their closest friends and relatives, much less the larger public – it's taboo. However, the taboo only serves to obscure the realities that many people live with. So, you might want to plug your ears for this next bit, because I'm going to get a little bit personal.

Skip ahead another two months (to January 2012) and I find myself going about my daily life, discomfort par for the course, and I come upon a very uncomfortable day. I can't quite pinpoint what's the matter, and all day it tickles at my unconscious until it hits me (kind of a slap, really): this is the kind of discomfort that I had before – before the doctor actually hitched my bladder back up, and the anterior vaginal wall with it. A bit of unsavoury probing determined that yes, in fact, my bladder had once again slumped down.

It was bulging into the vaginal vault. Aha! I declared to myself: this was why I felt like I had to pee every 20 minutes!

This was about the time I broke out the Google search engine. I had read through all of the materials provided to me at the time of the first surgery, and the surgeon had alluded to the 3% failure rate, but nothing really spoke of how the surgery was performed, not in the ‘we put your legs here, and the spotlight here, and then we cut here’. So, given the new situation, I thought it pertinent to find out just what had been done, and what was likely to be done again.

Wow. The Internet really will tell you – and show you – anything. Even things you didn’t really want to see.

Despite my misgivings (which are more along the lines of ‘Jesus, I really don’t want to do this again’ than ‘I don’t know if this is the right thing to do’), I made the phone call to the surgeon. He had repeatedly emphasised that, if I had complications, I was to call him – and I *had* waited the requisite six months. I figured that a bulging bladder constituted a complication. Miraculously, I was able to secure an appointment within two weeks: and not a moment too soon, as it turns out, as each subsequent day was greeted with a markedly greater bulge, to the point of protrusion.

Years ago (post-baby #1) my physiotherapist had advised Kegel exercises, and a specialty exercise that really must be experienced to be appreciated, while using tampons as an intervention (literally) for the slumping vaginal wall. This, of course, is temporary, and things like pessaries are the actual medical ‘tool’ used to prevent the wall from sagging in the absence of a surgical intervention (and there are something like 17 different pessary styles in current use). You may have had the passing thought, at this point, that goes like

this: “What on earth is your physiotherapist doing giving advice about internal problems?!” (I know it was a bit of a shocker to me – even more so the internal exam, which I will leave to your imagination). It seems that a certain very small, very select group of physiotherapists specialise in such things. Who knew?

Anyways, I reverted back to my old physiotherapist’s strategies in the intervening two weeks. Despite my heroic efforts, it was too little too late. Within the week, I had graduated from ‘bulge’ to ‘protrude’. It was like my vaginal wall had decided to simply roll over and die. Which led to this morning’s Googling of ‘bladder prolapse incidence’ and my subsequent discovery of “[emedicinehealth: experts for everyday emergencies](#)” (Lazarou & Christensen, n.d.). This helpful little website lists the Grades of prolapse from 1 (mild) to 4 (complete). My own self-assessment puts me at Grade 3 (severe). Of course, not content to take one (and an Internet one, at that) source as the Word, I followed another search hit to WebMD Women’s Health: Prolapsed Bladder (WebMD, n.d.) Well, this was encouraging: the ‘Symptoms of a Prolapsed Bladder’ reads like a Top 40 list of my current complaints, including such recent hits as “discomfort or pain in the pelvis, tissue protruding from the vagina (the tissue may be tender and may bleed), difficulty urinating, a feeling that the bladder is not empty immediately after urinating (incomplete voiding), stress incontinence (urine leakage during sneezing, coughing, exertion, etc.), more frequent bladder infections, painful intercourse (dyspareunia), low back pain.” Check, check, check.

When I considered the three main causes of bladder prolapse – pregnancy and childbirth, menopause, and straining – I started imagining what the doctor might enquire about. Did I have a baby in the past 9 months (because it had been nine months since the

surgery)? Nope. Am I going through menopause (apparently the decreased oestrogen levels lead to a slackening of the muscles and ligaments that hold up the pelvic organs)? At 37, it's not impossible, but it's also not likely. That leaves straining. And the myriad ways a person can strain. Which means we're going to have the poo-talk. I hate that talk.

There are pictures of me, at perhaps three years old, face screwed up in concentration, pain and effort, attempting to move what can only be called (and kindly, at that) 'sluggish bowels' (which begs the question of why, on God's green earth, my parents chose to capture such a moment, and put it in the family album to boot). My parents loved to advise me, when my children were toddlers, that 'prune juice works wonders for constipation – it was the only thing that worked on you!' So this is neither new nor particularly fond territory for me.

Then there's the straining that comes with having small children. There are times when you have to lift them – in and out of vehicles, on and off of diaper tables and toilets, in and out of tubs, up and down from your arms when tears and life require it – and there is nothing to be done about that, as far as I can tell. What I am supposed to say to my two-year-old? "I'm sorry, honey. I know you're scared of the pit bull, but mommy can't pick you up or her bladder may fall out!"

Then there's the 'weight-induced' straining-talk. Because let's face it: it takes more effort to haul around a bigger body, and your muscles aren't as likely to be either particularly toned or especially active, so when big effort is required, there isn't a lot of structural support, as it were. You do, literally, run the risk of straining so hard you explode – out of the only areas that such exploding can happen. Grim, perhaps even gross,

but factual nonetheless. And I am overweight. Not exceptionally so, but I'm certainly not in any danger of imminent starvation.

I made the call. The appointment is set for March. I can hardly wait.

She goes back to work researching in books, on the Internet, and she obviously comes across (eventually) what she was looking for. She is surprised. This is the point at which the sign comes down.

scene xviii January 2012: There is No 'Worm' in 'Ringworm'

I have a confession to make: I thought having ringworm meant you had worms. Yup. Now, I haven't taken any sort of survey on this matter, but I'm wondering if this is something like so many people thinking that influenza ('the flu') is the same thing as 'stomach flu' (gastro-intestinal upset). The bigger part of it stems from the fact that I've never known anyone with ringworm, and the name is just plain misleading. In any event, I feel foolish.

This is all thanks to an incident with my older son. He'd developed a scaly patch on his back, and it looked like the eczema that his brother suffers from. So, like any self-respecting mother, I whipped out the 'special cream' that we have for my littlest son, and diligently applied it for several days. Nothing changed, and after a few days I needed to concede pharmaceutical defeat. My son complained constantly about the itch, and I resorted to making an appointment with the family physician.

After presenting our case to the physician, she observed that it looked like eczema, but that, given it's unresponsiveness to some pretty potent corticoid molecules, it could also be ringworm. I made the appropriate moue, and she nodded in agreement. Honestly,

what I was thinking was: “Oh my god. My child has worms.” But on the outside, I was cool and collected, responding with, “OK, what do we do if it’s not eczema?”

She disappeared briefly, and returned with the ubiquitous samples. Her instructions were to “try this corticosteroid cream [yet another newly developed molecule] and if it doesn’t respond, move to a topical antifungal” (this should have tipped me off, but it didn’t). As we wrapped up the interview, she had absolutely no reason to think that I didn’t know what ringworm really was. This, in all fairness, is not her fault: there has rarely ever been something that has come up (and by now you know roughly how *much* has come up) that I didn’t have at least the basic knowledge. I didn’t even admit to my husband that I didn’t know. Why? Where is the shame in not knowing, given the vastness of the knowledge potentially available, and the reality that no one person, doctors included, could possibly possess it all?

Back at home, I couldn’t research fast enough: I needed to know more about ringworm, and even more so I needed to see pictures. How could this awful, unclean thing have entered our home? I told no one, instead choosing to ask my magic ball for answers – after all, the Internet, in its entirely indiscriminating, one might even say promiscuous, provision of information, does not, at least, pass judgment. Well, needless to say, I very quickly realised that there were absolutely no worms involved in ringworm. The relief! The pictures available on numerous dermatology sites looked nearly identical to my son’s rash, so after 24 hours of the eczema medication (and no change whatsoever) we moved to the antifungal. Within half a week the infection was cleared up, much to our collective relief. *She picks herself up, and essentially trudges back over to the medical area. She lies down with defeat upon the bed. She rolls away from the audience. The sign descends:*

scene xix February 2012: This is the Last Time (Again)

Eventually, she rolls to face the ceiling: this is where she directs her next comments.

Around this time, I made real progress writing this narrative, and then – radio-silence. Why? you ask. Was I on vacation? Was I unmotivated? Well, sort of. But more accurately, I was stoned, first on morphine, and then on oxycodone. That, and frankly pain makes it rather difficult to sit up at my writing table.

We’re up to six of these events. There was April-May 2006, then June 2007 (which was at a rural hospital, no less, but I didn’t mention it), March 2008, December 2008, June 2011, and now February 2012. These are the hospitalised events, not the ‘at home but still having a party’ events. If I were collecting points for these, my passbook would already be full.

Finally rolls over and addresses the audience.

This one took me a bit by surprise, to be honest. After all, I had already grandly declared “NO MORE.” Generally, I can look at the current conditions of my life and body and predict a meltdown. Stress is the key factor, of course, but a meal at KFC or Red Lobster the night before doesn’t typically help, either. But this time I had been exercising, getting sleep, eating well, losing weight, writing. True, extenuating circumstances in the extended family were a bit out-of-control, and there was a bit more on my plate emotionally and occasionally functionally, but nothing was direct and immediate and consequential to my husband or my children. Frankly, I was feeling pretty good about life. That’ll teach me.

Thursday (Feb 16th) dawned bright and sunny. I had a slight cold, and neither of my children was feeling fabulous. We were in family debate about going to Jack's Spanish class (which he generally loves), and had decided to lay low for the day when a friend called. As I rested on the couch listening to her tell of the medical turmoil of another family, I noticed the pain beginning. I ignored it for a few minutes, but then thought better of that strategy. While still talking, I wandered over to the cupboard and fished out my Tylenol 3. One tab in, I went back to the couch, listened to her and listened to my children playing upstairs, and tried to ignore the blooming pain. By the time the conversation ended, it was pretty evident that things were going south, and fast.

I crawled (literally) up the stairs and collapsed on my bed. There I called out to Jack: "Jack, honey, we have a problem."

Jack, alert and concerned, "What is it, mommy?"

Me: "Pancreas."

Jack, like a well-oiled machined, "Do you need me to call 9-1-1?" I could hear him fumbling with the telephone in the library. "OK, just let me know, mommy. I have one finger on the 9 and the other on the 1."

Despite the pain in breathing and speaking, I managed, "No, it's ok. We should probably call daddy first."

Next thing I knew he was beside my bed, phone in hand: "OK, what's the number?" What happened then was a series of dial-redial events. We have an understanding with daddy: If the phone rings repeatedly, despite being ignored and going to voicemail between attempts, it means something is really wrong at home, and dammit, pick up, because your

work meeting is just not as important. Six phone calls in he recognised the code and picked up.

Jack: “Daddy, we have a problem.”

Daddy: “What’s wrong, Jack?”

Jack: “Pancreas.”

Daddy: “OK, buddy, I’m on my way home.” Click.

Notice how we just have to say the one word, and it’s like our family’s code for “All hell is about to break loose”? And when we invoke the code, we’re not messing around – we really mean that drugs have not worked, ignoring it has not worked, and that medical personnel – or, to be more specific, their IV fluids and industrial-strength painkillers and antiemetics – are now required. So that’s where we found ourselves at about 10 am on that Thursday.

My husband arrived home and I, idiotically, opted to have him watch the children while I took another (ineffective) Tylenol 3. The retching soon began, and in between bouts I gave instructions about lunch preparation and piano practicing. This remained the situation for about another hour while I alternately took drugs and tried to strike various bargains with God.

I finally decided to go downstairs and request transport to the Urgent Care facility about ten minutes from our home. I curled up in a ball on the couch, and when that didn’t work (the children were eating lunch, so I couldn’t interrupt that), I went to the hallway nearest the door we’d leave through, and curled up on the floor there. While my husband herded the children to the door, he fielded questions and requests, like “Can I take this? Can I take that? I just want a few minutes to....(fill in the blank).” Finally, I had to

respond on his behalf with, “Mommy is very sick. We need to go now.” This caught their attention (mostly).

When we arrived at the Urgent Care facility, the first step (as it is with any emergency facility) is triage. Once you get to the front of the line (and this day’s was mercifully short), the triage nurse takes your personal information, and symptoms, including visual assessment and blood pressure. On this day, I was awarded, for appropriate incapacity, with a wheelchair. My husband trundled my chair into a corner behind a post (because he knows how much I hate vomiting and contorting in public), and we waited. Again, for a blessedly short time, and by the time I was called into the back (where all the fun stuff happens), I was somewhere near a 7 on my personal pain scale. My 10 is pretty spectacular, so I was hedging my bets.

They won’t let your husband back with you – they essentially dismiss him at the gates. Ostensibly this so that you can rest and the doctor can see you and assess you independent of any one else, but truthfully it’s so that they can screen for domestic abuse, and avoid any controlling spouse situations. From my standpoint, it would be nice to have company when I’m stuck for hours on an exam bed in a sterile room. But, the doctor has to ‘give permission’ for any additional people to cross the threshold: it can be like getting in (or out) of Sing Sing.

Once I had been taken into the trauma room, my vitals were quickly assessed (again), and they noted the elevated blood pressure and the lower oxygen levels. I was panting, but not really breathing, as an inflamed pancreas is compressed with every inhalation – and then pain is akin to fireworks. So you just don’t breathe much.

They began promising pain meds, but they first needed to stop the retching. The morphine they were planning to administer would increase my tendency to vomit, so step one would be taking blood, followed by finding a line, and then pushing a dose of Zofran. Zofran and I have met before: it's considered the Cadillac of antiemetics, and it's used with cancer patients. It's also used on me.

If you're tempted to think that I'm crafting this narrative after the fact, let me tell you something I find interesting: I was actually writing this in my head while I was lying in the brightly lit hospital room. I had two reasons: a) I didn't want to lose the moment, so to speak, and b) I had nothing else to do.

Once the heaving ceased, the nurse came in to inform me that the doctor had not yet ordered morphine. Wonderful. Why this was is open to speculation, including that someone missed the order of operations, or that they were trying to see if I was being overly dramatic. Another wait while the doctor arrived to determine that, yes, I was miserable. A nurse arrived with a dose of morphine, and I watched as every last drop was slowly pushed into the waiting port on my IV.

I can certainly see where people become addicted to morphine, especially that first moment when the rush hits your system, and everything calms right down. Things are instantaneously better. You can cope, you can think (you think), you can breathe. It's a pretty sweet feeling, if you can handle falling asleep at random moments, and speaking gibberish.

In any event, the nurse shows back up about five minutes later to re-assess my 'vitals' (blood pressure, temperature, blood oxygen level, all with machines) and check my pain level. Morphine depresses your breathing and lowers your blood pressure, so you

need to be monitored quite closely. I have a tendency to low blood pressure normally, so just add a little morphine to that (after the elevation from the initial pain is remedied), and you get a blood pressure that tends to scare medical professionals. At this point, my pain had backed off every so slightly, coming back down to about a 7 (from the 8ish peak a few minutes earlier).

Soon, the nurse came in to tell me that my lipase was not high – only 121 U/L, falling inside the normal range of <160 U/L (Council for Continuing Pharmaceutical Education, 2013). I tried to explain that, like all my numbers, from blood sugar, to caloric requirements, to body temperature, to blood pressure, my serum lipase was indeed inside the normal parameters for others, yet still sufficient to cause problems *for me* (and despite the fact that even the American Heart Association has recently gone on record, noting that “increased risk is defined arbitrarily” (Miller, et al., 2011)). I don’t know how many times I’ve gone over this tidbit with medical professionals, but it’s rare to find one who *doesn’t* look at me as if I’m a pathological liar. How could I *possibly* be so presumptuous about my biological *specialness*? So, with a serum lipase that’s certainly elevated, but not grossly so, they were certainly giving off the vibe that my pain level might not be commensurate with the numbers I was giving them. Which makes me delusional, a diva, or desperately in need of attention, albeit negative – take your pick.

With the arrival of these numbers came the arrival of the doctor, again. She was quite clear that “my numbers weren’t all that high,” and she also enquired into the whereabouts of my labs for my trigs. Regular monitoring of my triglyceride levels is something I do to make sure things aren’t on a slippery slope. Every six months or so I show up for the testing. She informed me that the most current labs were from December

2010, which would be prior to an umbilical hernia repair surgery whose story I haven't burdened you with. I must have looked completely baffled, because she followed this with "Sometimes time slips away on us." That was very understanding of her, but she also knew that I'd been hospitalised in June 2011 for pancreatitis/gall bladder (well, my chart knew this – it often remains to be seen whether anyone actually reads or absorbs this information, and this particular moment certainly seemed to indicate that might be the case here).

This is where the stupid-making effects of morphine really didn't help me out: what I *ought* to have said was "What about my labs from June 2011? They were poking me at 5 am every day, and I was NPO, so I assumed that they were running trigs, among other thing, seeing as I was there for a pancreatic episode or a gall bladder attack, depending upon who you ask." What I did say was, "Huh?"

The doctor then went on to 'explain' to me that they couldn't run the tests for trigs at this time because I wasn't fasting, and that it was a fasting blood test. As a result, they couldn't tell if my trigs were elevated, thus triggering the pancreatic attack. What *I* wanted to explain was that, like the chart (which actually looks like a manuscript) says, this was not my first rodeo, and that I knew all of this. I also wanted to add a little bit about talking with me rather than at me. But, thanks to the pain and stupid-making morphine, silence is what she got.

She then went on to let me know that "this isn't a hospital" (Really? I thought Urgent Care was a hospital! No, wait, hospitals are the places they actually call hospitals. Grrr.) and that I couldn't stay there (again, really?). I had already tried to explain to anyone who would listen, and to everyone else, too, that what I wanted was to get ahead of

the vomiting and pain so that I could go home to manage. I reminded her of this again, to which she responded, “Well, you can’t drink fluids, and we can’t legally let you go until you can.” Of course, no one had attempted to give me fluids, so no one knew if I could drink (and hold down) fluids or not. And, of course, I was legally entitled to leave if I wanted. That just doesn’t get mentioned too often.

So here we reached the “Let’s Make a Deal” portion of the program. We agreed that, if they gave me something more for the pain (and another antiemetic to boot), then the fluid challenge, and I could hold it down, then I could go, pain meds from the (tiny and stingy) in-house dispensary in hand. My husband, who had been permitted to see me only a short while prior, after 3 hours in the waiting room, looked at me as she left and said, “You’ll do anything to keep that down, won’t you?” He knows me well.

Shift change occurred, and a new raft of medical personnel needed to be briefed. A new nurse arrived, and when she checked my pain levels, she didn’t even blink – she left and returned shortly with another dose of morphine. As she administered this dose, I felt the awful surging pain (which comes with every breath) subside. She obviously noted my relief, because the fluid challenge was fairly quick to follow. A fluid challenge, for those not versed in such things, involves drinking small amounts of fluid (1 tsp. to 1 Tbsp.) every 5-15 minutes, and seeing if you can keep it from coming back up. You’re often parched by this stage, and make the mistake of pounding the fluid. What follows next is something reminiscent of Old Faithful.

I was able to sip the fluid with little difficulty. What did prove challenging was *remembering* to sip: by now I was so stoned on morphine that I was dazed and dozing. Every few minutes my husband would say “Remember to drink,” and I, annoyed (at myself

for not remember, and at him for being right) would say, “YES, I KNOW.” But without his coaching, I would have failed the fluid challenge.

By now our children had been with a friend for several hours, and we both felt the pressure of time and commitment. We decided that my husband would gather the children, bring them to Urgent Care, and then take them home – they would return to pick me up if I managed to escape. When they did return (and cleared security), they were most curious about the machines and tubes. Their dad and I gave an impromptu lesson on blood pressure, heart rate, and oxygen saturation levels as well as the anatomy of an intravenous set-up – cannulas, drip chambers, ports, sliding clamps and flow rates. Of course, it remains to be seen how much the 3- and 6-year old absorbed, but...they asked.

Jack began to feel ill, and so they left the facility. I discovered, upon their exit, that Noah had helped himself to quite a lot of my ‘fluid challenge’ ice water, and so when the new doctor arrived shortly afterwards, he took ‘my’ significant water consumption to be a sign of success. I did not dissuade him. This particular physician informed me, straightaway, that he ‘knew all about me’ from the departing attending. He went on to state plainly that if I did not want to go to the hospital, fine, that was my prerogative. Though it is impossible to capture on paper the nuances of a conversation, a bit of scripting might go a little ways:

Doctor: Well, now. I know all about you from Dr. N----. She says you don’t want to go to the hospital, so you are doing a fluid challenge.

Me: *(nodding)*

Doctor: *(a look of disdain)* If you’re in this much pain, we would prefer you go to the hospital.

Me: If I go to the hospital, then I'm just going to sit in a cardiac chair in trauma for 30 hours while they try and find a bed for me, and then all they're going to do is put me NPO and medicate for the pain. If you send me home with pain meds from here, I can manage by not eating and keeping my fluids up.

Doctor: *(surprised and displeased)* We can't write prescriptions in the ER. If you want to go home, that's up to you.

Me: *(now getting desperate)* So, you can't send me home with anything for the pain?

Doctor: *(with a certain air)* I can send 6 or 12 tabs home with you.

Me: *(frustration mounting)* So, what am I supposed to do then, if that's not enough? It's a long weekend, and walk-in clinics won't be open.

Doctor: *(shrugs)*

(Doctor takes his leave)

It doesn't take a genius to sense my incense at this exchange. He was in control, and he knew it: if I was 'insubordinate', and actually said the kinds of things I was thinking, and were true, he'd have security in there in a heartbeat (at worst) or I'd be left alone, and in pain, in the trauma room for an indefinite period of time (at best).

What kinds of things might I have liked to say?

Well, perhaps something like "Look, you can't really do anything for me that I can't do myself – medical science is limited in what they can do for pancreatic attacks, and really all anyone does is keep you from eating and feed you painkillers, and keep you hydrated, and hope that it all sorts itself out. I'm not so sick right now that I can't do this at

home – and I can monitor my own oral fluids, thank you very much, not to mention my urinary outputs. I even have the white cowboy hat!”

I would have also liked to add, “Once you send me by ambulance to the hospital, you put me into the ‘care’ of the trauma nurses and the ER doctors, and frankly, it’s a complete shitshow back there – the nurses, either because they’re swamped or they’re indifferent, rarely check on you, and they can’t do much unless they get the permission (‘orders’) from the doctor, and that individual is rarely seen. And many of the nurses won’t even bother to try and find the doctor, because they seem so calloused from their experience that caring is in truly short supply – that, and they think they know better than you your own condition. You’d swear you were on the frontlines of a battle, where triaging was born, rather than at an urban facility.”

If I really got going, I’d launch into, “And furthermore, why would you want me to go to the facility if I can manage at home? Look at my record. I’m not a rookie, and you don’t know so much about me and my condition that you should routinely second-guess everything I say. I get that you’re the ‘expert’ and, even more than that, the gatekeeper, but I am the ‘expert’ on me, and those stripes I have earned, I assure you, in the hardest ways imaginable. Do you resent that I know as much as I do? Are you bitter because I ask questions and don’t conform? Do you realise that I have small children that require my care, and I can’t just think about myself, or even more ridiculously, what *you* want? I have to balance everything and try for the most realistic outcome for everyone involved, and I do not have carte blanche to simply submit to the system and hope for the best.” As you can imagine, if I were to utter those words in the setting I’ve described, I would not find myself well-cared for – I would be disregarded, out of hand, as loud, irrational, perhaps even

dangerous. Despite the Hippocratic Oath, I am hard pressed to believe that this particular physician would have been big enough to treat me fairly in light of such an acrimonious exchange. And I don't think one can limit such a conclusion to physicians alone: any one of us would get our hackles up pretty fast under such an assault. It was the power difference that led to my attack fantasies.

So I, like many, many others, shut up and put up. It didn't help, as I've noted, that I was 'narcotically-incapacitated'.

I was, eventually, released, and went home to find my six-year-old vomiting because of the anxiety of my being in the 'hospital'. As soon as I arrived home, his symptoms ceased. Which, of course, begs the question about what would have happened had I been hospitalised.

Gets up, takes off the gown once again. She is looking more and more haggard as the scenes continue. Her earlier youthful speech and movement are noticeably diminished. She is aging, wearing down. The sign drops down as she moves CS.

scene xx February 2012: Critical Thinking for Breakfast

She alternates her delivery of the two characters' lines by shifting her position, or alternately using a readily available hand prop on stage, such as a stuffed toy.

At breakfast the other day, Jack (age 6 ½ years) asked me: "Mommy, what's better for me? Raisin Bran or Cap'n Crunch?"

So I asked in response, "What do you think?"

He thought a moment, and then said, "Let's look at the labels!" Over he goes to the cupboard, and drags out the two boxes. Now, I'm in the middle of some paperwork, but I see a 'teachable moment', so I'm loathe to dissuade him. He brings them closer, eyes

glued to the Nutrition Information panels. (We'll leave the story of how he knows such things exist for another day). "OK. This one (Cap'n Crunch) says 120. This one (Raisin Bran) says 180."

"What are you looking at? Calories? The energy?"

"Yes." He shows me the panels.

"Let's look at the serving size – are they both the same?"

"Yup. One cup. But the weight is different."

"Why would Raisin Bran weigh more?"

(thinks for a moment) "Raisins?"

"OK, then why do you think Raisin Bran has more calories?"

"Um...the raisins?"

"I think so, but let's look at the rest of the information. What should we look at next?"

Noah, my three year old, looks on with interest, aware that something is intriguing on the outside of the Cap'n Crunch box, rather than his typical interpretation, that of the fun being inside the box. This might be worth watching.

Jack surveys the information, and decides, "Carboxidratees."

"Carbohydrates. Complex sugars."

"Carbohydrates."

"And what about them?"

"Well, there's 29 in Cap'n Crunch, and...43 in Raisin Bran!!"

At this point, I grab the boxes: this is NOT what I was expecting. My initial thought (if we could be generous enough to say I gave it thought) was that Raisin Bran

would be “better” in all measures, comparatively. We look at them more closely. “All right, then – let’s look at the carbohydrates (the complex sugars), the sugars (simple sugars) and the fibre – what does that tell us?”

We determine that, yes, there are more carbohydrates in the Raisin Bran (due to the dried fruit, we think, and ‘better’ by virtue of being more complex in the grains), but there is also quite a bit more fibre (good for our intestines and blood sugar maintenance, I explain). Then Jack notes:

“Look here! There’s more protein in Raisin Bran. That’s good. And the fat...there’s a little bit less in Raisin Bran. But what’s this, mommy, this putosodium?”

“What?”

“This. Here.” He points to the Raisin Bran label.

“Potassium. Notice how it’s right under the sodium? Look at the two numbers. What do you notice?”

“There’s lots more putosodium—”

“—potassium—”

“—potassium in the Raisin Bran.”

“Right, the potassium is from the raisins. They’re both minerals that your body uses to communicate within itself, with something called the sodium-potassium pump, and you need them to be balanced, not all out of whack.”

“So this is good? There’s none in Cap’n Crunch.”

“Right. At least not worth noting. So which do you think is better for you, Raisin Bran or Cap’n Crunch?”

“Raisin Bran, even though there’s more calories.”

“I agree. But I think we should look at one more thing – let’s have a look at the ingredients.”

We read through both lists.

And we poured a bowl of Raisin Bran.

She crosses SL to the medical area. There are stirrups with oven mitts on them, and she puts on the ever-present gown, gets up on the bed, and places her feet in the stirrups. After some cringing and whinging, she gets back down, removes the gown, and crosses back to SR. She sits, and is obviously uncomfortable. Not physically so, but rather trying to write, and coming up empty, trying to read, and not focusing, etc. Eventually, she addresses the audience.

scene xxi March 2012: The Embarrassing Truth

Remember the ‘prolapse relapse’ I predicted in January? Remember the appointment I made?? I don’t really want to tell you what came of the appointment. I am embarrassed, and I would frankly rather not include the follow-up, but I can’t *not* include it. But it’s the perfect example of health ‘literacy’ gone awry, or possibly even AWOL.

So, just a few short scenes ago, I shared my graphic, self-assured pronouncements regarding the state of my bladder: frankly, because I have been scripting these moments in my head as life went along, I was *certain* that I knew what happened next. After all, I had my experiences, and some small portion of authorised knowledge from my research.

Well, according to my surgeon, I am wrong.

How wrong? You ask. On the bright side, my bladder ‘lift’ (with the mesh) is still holding. On the not-so-bright side, this means that the pain, leaking and bulging are *not* the result of a relapsed prolapse. The pain is of an indeterminate cause; the leaking is an

overactive or ‘spasmodic’ bladder (at least theoretically); the bulging is the unfortunate side effect of aging.

Aging. *Bulging*. Really? The way it was explained to me was this: “You know how, at the end of the day, your feet swell? Well, the pressure and weight of other organs, during the day, can cause the settling and ‘bulging’ of the bladder at the end of the day.” So, instead of saying to people, “You know, I really need to put my feet up,” I get to say, “You know, I really need to get my bladder off its feet.”

As for the spasmodic bladder, this is not an entirely new concept. At the time of the preparation for the prolapse repair surgery, I had to undergo a ‘bladder stress test’, which involved backfilling my bladder to measure its capacity, and whether at any point it began spasming. And yes: the experience *was* as awesome as it sounds. The only discovery made at the time was that I had a ‘less-than-average’ bladder volume. So when I had previously joked that I had a bladder the size of a walnut, I was not altogether inaccurate. It had been mentioned at the time that, should my bladder start to exhibit signs of ‘overactivity’ (which means you feel you need to pee all the time) then the only real intervention was medication. I had thought, though, that I had dodged that bullet (having been hit by numerous other bullets in the meantime).

Given how I was presenting, my surgeon determined that I had developed an overactive bladder in the preceding year, independent of the surgery (because post-surgical overactive bladders are only to blame within about six months of the surgery), and I could do two things: the first was to ‘train’ my bladder to behave better, and the second was to take antispasmodic medication.

In the first instance, whenever a bladder spasm occurred (you know you're having one when you have an uncontrollable urge to pee when you have no reason to), the strategy was to wait it out. So, let's say you need to 'go' every 20 minutes. Well, you wait through the 20-minute 'need to pee' spasm, and go at 25 minutes. Then, when the bladder learns that the 20 minutes is now 25 minutes, and starts spasming at longer intervals, you stretch out your training cycle. The idea, of course, is to train your body to get through these intervals until they move further apart and, I suppose, theoretically into extinction. Except your bladder is not a dog, and you are not Pavlov.

The second recourse is medication. It turns out that there are two commonly prescribed medications for spastic bladders, at least in my neck of the woods. The first is much cheaper than the second and, as such, insurance companies require that the cheaper drug be tried first before the second may be employed. The catch with the cheaper drug is the side effects, the most notable being abominable dry mouth. I was sent out with prescriptions for both, but I was also sent away with a 14-day supply (pharmaceutical rep samples) of the more expensive brand, and so I tried it first. I figured I'd be able to identify the deficiencies in the cheaper medication more quickly, because I'd know what the more expensive (and apparently more tolerable and efficacious) medication was like. I decided to read the medication's insert before I started, just for argument's sake, thinking that it would be fairly innocuous.

And here's what I discovered: according to Astelas Pharma Canada, Inc., the manufacturers of this medication, "the most common side effects reported...were dry mouth and constipation. You may also experience dry eyes, urinary retention, and blurred vision" (Astelas Pharma Inc., n.d., p. Part III). This is a nice way of saying that the

medication dries you up – but what I don't get is where this water goes. Presumably, given the wording, it stays on board – so that means bloating, doesn't it? The leaflet goes on to say, "This is not a complete list of side effects. The following events have been reported in association...in worldwide postmarketing experience, although the frequency of events or a causal relationship...could not always be confirmed: urinary retention; vomiting; peripheral edema (swelling in the lower limbs); hypersensitivity reactions including rash, pruritus (itch), and urticaria (hives); dizziness; headache; and hallucination." At about this point, you begin to ask yourself if needing to pee more frequently is a small price to pay in comparison to that list of potential new problems.

If this was the list for the more costly of the 'solutions', then I wondered at the less expensive medication, which I was told had 'more noticeable' side effects. I supposed that I would learn about that in about 11 days. And why would I choose such a path, knowing that such things are possible? It was a calculation, really. While not in the 'pee every twenty minutes' group (thank god), I was still in the 'pee-multiple-times-a-night' group. It's one thing to be sleep-deprived because you're dealing with a newborn (cuddling is a reasonable – most times – compensation). But being sleep-deprived because you're dealing with a spastic bladder? Well, there's a little less consolation in that.

That leaves the pain. It's determined to be indeterminate – and that, in itself, is a ridiculous statement. However, with no clear cause, there is no clear solution – I'm offered respite through Tylenol, but not much else.

And there you have it: the embarrassing truth. I don't have a recurring prolapse – I have a spastic bladder and an aging body. I was so sure, and I was so wrong. Is this because I'm a layperson? Is it because I didn't have all the information? Is it because,

despite the Boston Women's Health Book Collective (if you don't know what that is, look it up), I really can't check out those body parts without help? Is it because I misread something? I simply don't know.

Removes gown again, and being pacing through the CS area. The light should follow her, but in fits and starts. She should seem hard to track.

scene xxii March 2012: Groundhog Day

Last Monday I caught myself thinking about thinking. And then thinking about thinking about thinking. It sort of felt like the movie 'Groundhog Day' or one of those pictures within pictures within pictures, ad nauseam. To be honest with you, it's driving me insane. But what caught me is the feeling, the surprise when I realised precisely what I was doing and the gaps I was nonchalantly skimming across. In the moment it happened, it was like a spectacular floodlight washed over me, the thought process, and Aisle 3 at Shopper's Drug Mart.

I had just finished taking my boys to the walk-in clinic for colds that would not respond to the normal at-home treatments: We were given 10-day prescriptions for amoxicillin, and we were at the pharmacy getting them filled. This was an opportunity to stock up on some of the supplies that had run down in the preceding days, things like Tylenol and tissues and chest rub. It was this last item that caught me out: the chest rub. The thinking went something like this:

Oooo, I need some more of that. There's the Kalaya. One of those. Hmmm, mom suggested I use Vick's. I should go look at that. Oh, look – they shelve the Kalaya over here, too. Hmmm, Vick's Baby Rub. That's the stuff. What's in this? Oh, it has menthol AND lavender. The lavender would be nice. Jack loves lavender. So what does the

Kalaya have in it? No lavender. Menthol and eucalyptus. Hmmm. Should I get the one with the lavender or the one without? I suppose I should look more at the labels. Vick's Baby Rub, first ingredient....petrolatum. Oh. Kalaya first ingredient....soy. Well. I guess I'm getting the Kalaya. It doesn't have a petroleum product as its base. That's a better choice.

But why is that a better choice? I don't really know if the petroleum actually harms them. Does it cross the skin barrier? Well, I don't like the idea of a petroleum product when I can use a natural product. That's got to be better.

I'm a hypocrite. The soy is farmed with petroleum-intensive methods, probably. Maybe it's a Monsanto product, like the Round-Up Ready seeds. Maybe the soy is covered in pesticides and herbicides, and it's really more toxic than the petrolatum. How can I know this? How could I find out? Maybe I'm doing more harm by choosing the 'natural' product over the other.....

I'm stuck now. I'm thinking about how I'm thinking about this, and now I can't decide which way to go because now I know that I don't have adequate information to make an informed choice. I'm not even sure I could get the right information if I tried. Jesus. This is ridiculous. I'm having a crisis over chest rub. I need to go home and write this down.

And so I picked up the Kalaya, paid, went home and slathered it all over my children. But I did so with the lurking feeling that I was somehow harming them and that my 'health literacy' was somehow failing in this regard. Have you ever suffered an existential crisis over chest rub? I thought not. This thinking about thinking is perhaps not all that it's cracked up to be.

She turns on heel and returns, once again, to the clinical setting. She is becoming very lazy with throwing on the hospital gown. Her whole demeanour shows she is becoming worn down, almost apathetic. She picks up the sign from her bed, and shows the audience, before throwing it offstage.

scene xxiii July 2012: Don't Wear Tight Shoes

I recently underwent an EMG (electromyography) study for “unexplained muscle twitching and spasming in my right leg.” Did you know there is a difference between a twitch and a spasm? I didn't, until recently. It seems that a twitch is an uncontrolled small movement in a large muscle that can be seen under the skin, whereas a spasm is a contraction of the muscle that can be painful and may (though not always) resolve quickly. Think: Charley horse.

I had peripheral neuropathy in that same leg, supposedly from nerve damage sustained during the gestational diabetes I'd developed with my first pregnancy. Pain and dysfunction (as in a dropped foot) are the upshot. However, that had disappeared after about two years of physiotherapy. This new twitch was some five years after that fact, and was therefore suspicious.

In any event, I'd frankly forgotten that I'd been referred for this testing – it had been ordered months ago – when I received a call asking if I'd come in on short notice. After a wild scramble for childcare (my husband had a Stampede party and was therefore 'unavailable'), I committed to what was likely to be an unpleasant experience – many years prior I'd had testing for carpal tunnel syndrome, and I still call it 'my electroshock therapy'.

When I showed up the next day, for the first appointment of the afternoon, I was operating under the assumption that my 30-60 minute appointment would be just that. My first hint that this would not be the case showed with the introduction of the neurology fellow that was going to be doing the test prior to the attending neurologist reviewing the findings. Given the bizarreness of my medical history, I've met and taught many a fellow, resident, intern and clerk, not to mention my share of attendings. Everybody has to learn, and I do appreciate the freak-show nature of my medical history. It was about the time, however, that the EMG tech was teaching the neurology fellow how to use the machine that I got the sense this might take a bit longer.

In this type of testing, electrodes are placed in certain places on your skin that mark where a nerve impulse will travel to: for instance, nerves run down your legs to your feet – so they place the sensors in places where the nerves end – then they apply electricity to spots further up the chain, so to speak. They then, more or less, compare what they've zapped you with with what comes out at the end, thus getting a picture of how a nerve is functioning (or not). And they keep increasing the amount of electricity they're zapping you with to get a 'full picture'. It's awesome.

After repeated tests (and some big shocks - literally), they left the room, only to return with the attending. I was informed that, based on the studies, I had the nerve conductivity of a 70-year-old, not the almost-40-year-old's readings I should have had. As such (and because I was actually present when they reviewed the findings), they wanted to continue to test me, moving on to a 'needle study' (the intramuscular version, involving needles and fine wires), and then replicating a number of the conduction studies from earlier in the afternoon. When I informed them that I needed to call the babysitter to ensure

that she could stay, I received more than a few raised eyebrows. Evidently my reaction was not the norm (what was I supposed to do? I had told the babysitter I'd be home at 3 pm at the latest – I had foolishly, I suppose, used the timeline I had been given on booking to manage my babysitting time).

When I asked the Fellow whether the needle study would hurt, he waffled, as in ‘Um...uh...’. Advice for physicians: Tell the truth. If you don't know, say so; if you have patients that have experienced pain, say so; if that pain may be severe, say so. The attending came in, and stated unequivocally that it *might* hurt, and that it depended upon the patient. Fair enough. They inserted needles, wired me up, and started up the generator, so to speak. The whole thing was somewhat Frankensteinian.

Throughout this entire (lengthy) process, I was asked many, many questions. I was throwing about terms like ‘stenosis’, ‘early-stage osteoarthritis’, ‘L-3-4-5’, ‘prolotherapy’, ‘peripheral neuropathy’, and ‘flexion’. The tenor of the conversation quickly elevated to a high-level medical discussion of my previous, current and future diagnoses and prognoses. Soon I was getting the play-by-play of the oscillations, amplitudes, and velocities involved in the testing. Frankly, I was out of my depth, having paid marginal attention to this aspect of my high school physics courses. Conceptually I had a clue, if only half. But technically – not so much.

The medical professionals (including the attending neurologist, the neurology Fellow, and the neurology tech) had no idea. While I was lying there, I was actually thinking about this – I was intentionally using words and watching for reactions. I was almost running my own little conduction study.

Weeks later, I was able to finally see the write-up of my case (it was ‘lost’ in the system for quite some time, no doubt thanks to a server fire that occurred the very afternoon of my appointment). In the neurologist’s write up of my case, forwarded to my physician, were included these words under “Impression”: “We brought to her attention to avoid wearing tight shoes and to be careful when washing her hands to avoid damaging her skin” (Eesa & Alanazy, 2012, p. 3). It is actually signed by the neurologist (though dictated by the Fellow), and it is a part of my permanent record. Neither of these facts would be particularly remarkable, except for the fact that we *did not* have anything that remotely resembled such a conversation, and that those words are very obviously from a report written for another patient. This, remember, is the information authorised by the *expert*.

Off goes the gown, and over to the home she trudges. There is now a slight limp. The books are almost obscuring whole areas of the stage at this point, having accumulated throughout all of the previous scenes. She pushes some aside, with a bit of difficulty, and eventually finds a place to sit. She roots around until she finds her sign:

scene xxiv August 2012: There Really is a ‘Worm’ in Hookworm

Continuing in the vein of ‘strange conversations with a six-year-old’, yesterday marked an intense discussion on tropical diseases versus temperate diseases. I’m not entirely sure how it happened: It seems that it started with a discussion of poverty, particularly in equatorial areas. My son has a particular interest in history, culture and geography, and many of our conversations involve these. Soon I was explaining the lifecycle of the hookworm, and its effects on the life quality and expectancy of those infected. I don’t think I went so far as to introduce the terms ‘morbidity’ and ‘mortality’,

but that day can't be far off. He then proceeded to quiz me on treatments and the habitat requirements of the hookworm. Having recently read up on these, I had ready answers (miracle of miracles). When he determined that desiccation or exposure to direct sunlight would kill the ova and/or larvae, that using toilets (even latrines), wearing shoes and washing your hands would reduce or eliminate the risks (not to mention that we don't receive the requisite 40"-plus rain needed for their proliferation), he relaxed. He stated, "We were lucky" that we didn't have such awful diseases.

Oh, the teaching moment that was upon me: I could have just agreed with him, but no. Something possessed me to go on to explain that the temperate areas have their own particular problems. With affluence and the lifestyle (and longevity) that it affords for many, comes a host of other diseases, ones which he was arguably susceptible to in his life: diabetes, cardiovascular disease, back and joint problems, among others. This, of course, segued into a discussion of lifestyle choices that would affect this, including diet, exercise, and stress management. He vowed to stay healthy and active so as to circumvent these problems later in life. I congratulated him on his smart choices, which led him to make some very pointed observations about the choices his parents were making.

Again, here I was: more and more aware of my role teaching and modelling health behaviour for my children. Instead of just *doing* it, I was increasingly *thinking* about it. You know the scene in the Wizard of Oz where Dorothy realises that the 'Great and Powerful Oz' is nothing more than a wizened, cowardly man using, essentially, clockwork and smoke? That's how I was starting to feel. And not only about the medical system or culture or notions of health: no, I was beginning to feel this way about *myself*.

It was mostly a disheartening feeling, really: that, and disillusionment. The promises of a previous age, both my youth (and relative health), and my ever-expanding realisation that cultures are limited, systems are limited, knowledges are limited, technologies are limited. *I am limited, and my children will be limited as well, by chance and circumstance.*

She walks to CS, as a single spot floods where she stands. She is close to the audience. While she stands there, a stagehand brings her the sign, in the fashion of an acting award. She accepts it likewise. She acknowledges the audience, and then hands the card back to the stagehand.

scene xxv October 2012: And the Oscar Goes To...

Thank you. Today, October 15, 2012, I gave a beautiful performance. It has now been three years since my oldest son was (perhaps, maybe, ostensibly) affected by 2009's H₁N₁ influenza 'pandemic', and today, for the first time since then, I have both considered, and then obtained, the influenza (H₁N₁ strain) immunisation for my children.

This is a major shift for me, and before I get into the recap of my performance, I want to spend a little time considering how I have once again arrived at a place where I (relatively) calmly immunise my children. I suppose that there are several ways to interpret my actions, especially when taken against the history I've presented to date. The first is that I've just given up: I'm too tired to think any more about things, to research them, to question them – and, as such, I've decided to absolve myself of personal duty and I've simply handed it over to "the experts". OK. Fair enough. The second is that I have become convinced of the efficacy of vaccinations as a means of ensuring my children's health, especially in light of our run-in with influenza in the past. I've decided to let

science triumph, or perhaps scientific literacy, or even perhaps ‘cultural literacy’ as it applies to vaccinations. I can see this, certainly. A third possible interpretation is that I have taken an altruistic approach, the one where I realise that herd immunity relies on all of us to do our part, and that if we let too many slip through the cracks, then we put those that are truly in need of that herd immunity – those with various cancers, immune deficiencies, prematurity, or developmental disorders that predispose them to infectious diseases – at great risk. Those of us that can handle the vaccinations are duty-bound by living in society to protect those that are weaker. This, too, is completely reasonable.

Maybe a fourth possibility comes to your mind, too, one where I’ve decided that frankly we don’t really know as much as we think we do, but that the benefits outweigh the risks – this isn’t passivity, or complacency, or righteousness or even logic. It is a ‘I know that I don’t know everything, but my experience tells me that this should be done in light of no compelling evidence to the contrary’. You could argue that I have been persuaded by the Western techno-medical capitalist enterprise that governs our thoughts and actions through cultural manipulation – through policy, advertising, social marketing and power structures and relationships. This is very possible, too. I acknowledge that all are conceivable, perhaps even probable.

To call something a ‘leap of faith’ may make many rationally-fixated individuals uncomfortable. After all, much of the techno-medical structure is fond of relegating the emotional or spiritual to a tangential or sideshow position. This is not something I say flippantly. However, I think that, despite all of our efforts to be ‘logical’, at the end of the day we do not possess all of the facts, not ever, and therefore even the most scientific of endeavours has “the educated guess” factor added in. And what is an ‘educated guess’ but

a leap of faith, between what you're pretty sure you know and what you're pretty sure you don't know?

So, to today's performance. Why 'performance'? you ask. As a trained performer, there is an awareness that you attain – it can be felt. When you have been working on something for a period of time, developing your characterisation, the ways that your body, your voice, your manner of speaking, even your manner of thinking, begin to take on an almost-independent quality. By this, I mean that this character begins to live and breathe out of your being; There ceases to be conscious intent. This character is both 'you' and 'not you'. As a performer, on stage, you can actually internally step back and watch and listen to this 'other' that is also you. You can actually think about other things while this character exists alongside you, but it is neither mindless nor automatic. It is as if you have split your mind into two, and in some ways, your 'real' body shifts into an internal space where it waits. You can also, certainly, immerse yourself, and that distance between 'you' and the 'other/character' can become almost undetectable, but unless you're suffering from a psychotic break, you still know you are you, and the character is the character.

I offer this as an explanation for what occurred today. Today, going into this appointment, I was both aware and ready for my performance as 'health literate mother getting vaccinations for two small children whom I am also training in the way of health literacy'. Not a catchy title, I realise. However, having been through all of the various thought-processes and subject-positions outlined above (and undoubtedly more), and having arrived at a moment where I was ready to vaccinate again, I did so from an agentic standpoint. I had both a good idea of what I knew and what I didn't know, and was prepared to make that 'leap of faith' onto the stage.

I had my props: I had both boys' Alberta Immunisation Cards, their Alberta Health Care Cards, my 'Get Organised' health and wellness planner, a pen, and an iPad (for those unforeseen delays). I had my costume: I was neatly dressed and groomed (as were the boys) because, despite what anyone might say, appearances count. The set was the public health office near our house, and we knew our cues – where to park, where to enter, when to enter, where to line up, where to stand, where to sit, what do while waiting in the wings.

Watching the performance unfold, we witnessed the nurse come and gather our files, making no eye contact with us – it was, after all, a 'fourth wall' and we weren't supposed to be recognised as players yet. We waited 25 minutes for our call (front of house obviously had some problems getting everyone situated), so we quietly amused ourselves with idle chit-chat and technology.

Our cue came, and we entered the playing space. One casting change had occurred unbeknownst to us: an additional nurse (this one in training) had been added to the ensemble. Our first scene took place in the hallway of the nurses' corridor. My youngest required a height and weight check in order to be charted for growth and development (having reached 4 ½ years twelve days prior). He knew his part quite well – shoes off for weight, heels against the wall for height.

Our second scene was to be played in a small, clinical room, with enough seating for the five members, and a view of the parking lot. This is where the real meat of my role was enacted. The players exchanged the scripted niceties, and the 'informed consent' portion of the play began. The first item of business was to review the vaccinations scheduled: this portion of the narrative line drags, and requires real artistic commitment.

Some of the younger players lose their focus and motivation during this portion, and the more senior members of the troupe have to work harder to keep the through-action moving.

At this point I could feel my characterisation really emerging - I nodded knowingly and provided the correct terms before the nurses, enhancing the appearance of spontaneous exchange. Diphtheria, Tetanus, Pertussis, Polio (DTaP-IPV) rolled off my tongue, as did Measles, Mumps and Rubella (MMR) and Pneumococcal. I expressed appropriate pleasure at the news that the current Pneumococcal vaccine was for thirteen (!!) strains of the bacteria.

The dialogue takes on a new energy when the topic of influenza comes up – the excitement in the air is palpable when they realised that we were going to undertake the vaccination – today was, after all, the very first day of the season’s immunisation clinics (Dorner, 2012), and while the actual clinic times didn’t begin until 11:30 am, we were at an early morning vaccination appointment already, and they were willing to administer the vaccine before the appointed time! We were, in all likelihood, the trail-blazing Vaccination Vander Valks of South Calgary.

In discussing the booster that my elder son was going to receive, as well as the impending influenza shot, I engaged them in a deeply contemplative dialogue about transient hypogammaglobulinemia with provocative teasers like (after delivering, almost pitch-perfect, the troubling pronunciation) “I take it you’ve never heard of it?” I elucidated the various components – the IgG, the IgM, the IgA, and so forth. They responded with genuine interest.

From here, they directed the conversation towards the nature of the virus used for the vaccinations – here, my improvisational skills were tested, as I hadn’t gotten the

amendment to the script where the availability of both a live and a dead virus were outlined. I kept my characterisation intact as I worked through the new information, extrapolating (on the fly) that a live vaccination was potentially (however small that potential might be) more risky than the dead vaccination, at least for a child with an immune deficiency. They suspected nothing.

This performance was also something of a Master Class. The junior members (my children) were there to both play their roles as well as to learn at the knees of a master. My experience and expertise in the role of Health Literate Mother gave me the chance to display in a tangible manner the nuances that such a role requires. I was, of course, reprising my role – it is perhaps my most convincing and well-known role – but each subsequent performance develops layers of subtlety and naturalness that earlier performances lacked. In any event, my little learners (especially the seven-year-old) were rapt in their attention – at least initially. I could feel their attention to the subject at hand wane with each new piece of terminology. This eventually led to a jab in the ribs. I moved the narrative forward.

I explained, by way of transition, that this entire preamble was necessary to “Informed Consent.” Taking the cue, the public-health-nurse-in-training stated: “I need to know: do I have your permission to vaccinate you?” “Yes.” Turning to Jack, “Do I have your permission to vaccinate –“ “Yes” (says Jack) “—Jack?” “Yes” (says mom). “Do I have your permission to vaccinate Noah?” “Yes” (says mom). Blank stare, says Noah.

The nurses provided their knowing comic relief at this point, finally expressing their curiosity with the (now standard) question: “Do you work in health care? Are you a doctor or nurse?” You see, this is the moment when I know that my performance has been

outstanding: when “Acting” transcends the stage and becomes so convincing that the audience believes that you are the character, and that the script is your natural being. You could be one of *them*.

scene xxvi November 2012: And So It Begins Again

The lights come part way up across the stage. The narrator steps forward onto the apron to address this first portion to the audience, as the sign descends, and stays.

And so we begin our final scene. Not because it’s ‘over’. Far from it. Mostly it’s ‘over’ because it just *is*. Enough pieces have been thrown together to give you a Monet-esque picture of the high (and low) lights of this idea I’ve been exploring experientially – an exploration of what health literacy might mean through a life-as-lived. Or maybe it’s more Picasso-esque, or even Pollock-esque...Regardless, you have an impression – thoughts, feelings, images, words, moments in a life that are remembered, some more immediately than others, but all, of necessity, recorded after the fact.

Crosses over to the ‘home’ area, where she remains until the crossover to speak about the clinical portion.

I will leave you as I met you: with a story.

Early Saturday morning in late November 2012, I woke up with an intensely aching lower back -- but only on the left-hand side. This is the kind of pain that is so deep within that you cannot seem to pin it down or escape it. I couldn’t talk coherently; I was whining and whimpering for the better part of the day, really being quite a boob. Attributing it to a pinched nerve, I medicated myself and prayed that it wouldn’t last too long. I gave no thought to visiting a hospital. It’s common knowledge, and something I’ve talked about already, that the medical establishment can’t do much for back pain. I can’t count the

number of people with whom I've shared the emergency room's hallways, who, like me, are convalescing in cardiac chairs. If I'm there for one of my pancreatic 'episodes', I have some hope of legitimation through admittance as a 'real' patient. They, on the other hand, have little prospect of relief beyond a handful of painkillers and a recommendation for physiotherapy or advice to return to their Family Physician's office during "regular office hours" in order to be referred for an MRI, which will take months, if they're very lucky. I have heard a few classy physicians counsel overweight patients presenting with back pain to "get some exercise." Publicly.

So, no thought of a hospital crossed my mind. Not even the following Tuesday when, while showering in the early morning, I felt a fire-like pain rip across my lower back from left to right. In that moment, my legs collapsed, and I ended up prone on the shower floor. None too flattering, I assure you.

As I was lying there, beyond the immediate concerns of pain and taking care of little boys in the absence of any assistance – and to be fair, no one knew I was collapsed – my primary concern was aesthetic. It's true. The thought of such abject, grotesque, corpulent nakedness trumped any more practical desire to seek help, even though I had taught my children to call 9-1-1.

While lying there, trying to grasp the extent and significance of the pain (and while the shower wand whipped wildly about my head), my littlest boy came and opened the shower door. He was surprised to find me not where I was normally: upright. Slightly confused, and a bit insulted, he snaps, "Mommy! Why are you on the floor?!" I, not wanting to traumatise him, could only respond with: "Mommy's taking a break. Shut the door."

Thereafter ensued about a 45-minute period where, while still lying on the floor, I calculated how I might use the shower bench to get myself up and out of the shower. I don't remember a lot of the details, but I do know that I found myself about 30 feet away lying on my bed with the remote control in hand. This was to be my parenting strategy for the day. Feeding the children that day proved interesting, considering I couldn't move. Mostly they foraged.

The next day was memorable only insofar as there were new experiences in creative mobility. The "pinched nerve" that I had diagnosed myself with had seemingly shut down the nerve sensations, and much of the motor control, in my right leg. Still, this didn't strike me as particularly odd. I took to calling my leg "peg leg", because I felt as if my leg, from the knee down, was not mine. I remembered with some (admittedly black) amusement Oliver Sacks' memoir "A Leg to Stand On" (1984). I began to appreciate his perspective.

I woke Thursday to muscle spasms. Or maybe twitches. Whatever they were, they moved all over my leg - thigh, calf, front back, sides - over and over again they jumped in different patterns and with differing speeds. You could actually *see* it - I called the boys in to watch.

"Aha!" I thought. "My pinched nerve has released and my nerves are resetting! Great!!"

Not 'great'. Also, not 'right'. After the daylong twitch subsided, the pain level came down (happily): what didn't change, unfortunately, was my mobility. If anything, I was weakening. Now I started to consider this might all be a bigger problem than I had originally anticipated. Still, the thought of calling my family physician and booking in for

something that would, in all likelihood, have passed long before an actual appointment time was available, made me wrinkle my nose.

She now hobbles over the 'clinical' area. There is a pronounced lurch in her gait, stemming from her insensate right leg. She doesn't use any assistance, just sheer will, to get across the stage. This should, under no circumstances, come off as pathetic, or like a caricature.

After the days of pain and immobility, I finally speak to my doctor, but only as afterthought: I was there for another matter. Her concern becomes alarm as our discussion progressed, describing the symptoms, checking the charts. Next it was a whirlwind: an 'urgent' MRI five days later; a phone call from the radiologist the next after (to my doctor, not I); a visit to my doctor the next morning, briefed on radiologist's findings (classed as 'urgent', but not 'emergent'); a referral to a neurosurgeon; scheduled appointment with the neurosurgeon for three weeks thereafter (miraculous in the Christmas season); and a long list of "if any of the following occur – increase in pain, decrease in mobility, loss of bladder or bowel control – present immediately at the hospital" (the one with the fancy neurosurgical equipment and neurosurgeons on call).

Driving, parking, walking, taking two elevators, I (and my husband) finally arrive at the spine clinic. After a respectable (but not long) time spent in the 'waiting' room, a man in a short white coat summons me. We follow, relieved to finally meet the neurosurgeon.

But this is not the neurosurgeon. Who is this man? He says something to me, but his English is so heavily accented that even I, who works with voices, cannot tell what it is. Asking him to repeat himself is fruitless, he looks at me like I'm from another planet.

I gather he works with the neurosurgeon. Is he a fellow? A resident? An intern? A clerk? A colleague?

He will ‘take my story’, and he will ‘discuss it with the surgeon’; they will ‘tell me my options’.

A male voice, heavily accented, acts as the ‘doctor’, piped in from offstage: the narrator attempts to remain civil and helpful throughout the conversation, despite the mounting tension. The voices alternate below.

Man: Tell me about your pain.

Me: (hesitant) Ok....what do you want to know?

Man: Just tell me about your pain.

Me: Um, uh, well, started about a month ago—

Man: It started on December third?

Me: Well, no—

Man: You said a month ago. When did it start?

Me: Ummm...about four weeks ago?

Man: It started on December sixth?

Me: Sure. *(aside: I’ve since done the math: It ‘started’ on November twenty-third.)*

Man: Well, when did it start?

Me: December fifth. *(aside: A complete lie: But this is the first question, and*

already I’m unnerved.)

Man: OK, and...?

Me: It started with a deep aching pain in my left SI joint. That last about three days.

Man: So, it lasted until Sunday?

Me: No, it started on a Saturday, and this pain lasted until the Tuesday (*aside: this, of course, should have been HIS clue that I hadn't given him an accurate date.*)

Man: Did you do anything to initiate the pain?

Me: No.

Man: You did not lift anything.

Me: No.

Man: You did not strain?

Me: No.

Man: You did not fall?

Me: No.

Man: So you did nothing to cause the pain.

Me: NO. (*aside: This should have been MY clue that this was going to be painfully long history-taking, not a story.*)

Man: Out of ten, what would you rate the pain?

Me: TEN (*aside: I loathe this question.*) Then the pain changed: there was a

feeling of fire across my SI—

Man: Your lower back.

Me: No, my SI.

Man: Your LOWER BACK.

Me: NO. Not my lumbar region: my sacro-iliac joint.

Man: This was not your lower back?

Me: NO. (*turns around and gestures to lumbar region*) This is my lower back.

(gesture to where the SI joint is located in her bottom) This is my SI joint,
where I felt the pain.

Man: OK, you had deep aching pain for three days, and then a burning pain across
your SI joint. You did nothing to cause the pain. Your pain was 10.

Me: Yes, but you didn't ask me that: you only asked me about the aching pain.

Man: I asked you about the pain.

Me: No. You asked me about the first pain, and I told you ten. You did not ask me
about the changed pain. It was also a ten.

Man: (*annoyed*) Yes, yes. What else about the pain?

Me: Well, I couldn't move--

Man: How couldn't you move?

Me: I couldn't breathe. Walk. Climb stairs. Go to the bathroom. Take care of my
children.

Man: So there was pain that affected your breathing and walking?

Me: *(through gritted teeth)* Yes. That lasted for about two days, with numbness and
lack of mobili—

Man: No, no.

Me: Sorry?

Man: That has nothing to do with pain.

Me: *(aside: What??? That has everything to with pain! Doesn't it? Good lord, do I
not even know what pain is anymore??)*

Man: That is numbness. We will get to that later.

(Silence)

Me: Uh...well, what do you want to know?

Man: I do not want to lead you; tell me about your pain.

Me: Well, on the second day all of the muscles in my leg starting spasmin—

Man: NO, NO. I did not ask you about that. Tell me about your PAIN.

Me: *(frustration showing through)* Well, what would you like to know?

Man: *(condescending)* MA'AM. I asked you about your pain. I do not want to
lead you. You must only tell me about your pain.

She finishes the interview, and stands up, near bed, to address the audience.

I endured this event much the same as I have endured everything else I've told you about: with a combination of fascination and resignation, and often (after the fact) a sort of

black amusement. I have tried to spare you the academic in this account, because I wanted it to mostly reside in the land (and language) of experience. But I think that philosopher Judith Butler has, far better than I, the words I want to leave you with:

My account of myself is partial, haunted by that for which I can devise no definitive story. I cannot explain exactly why I have emerged in this way, and my efforts at narrative reconstruction are always undergoing revision. There is that in me and of me for which I can give no account. But does this mean that I am not, in the moral sense, accountable for who I am and for what I do? If I find that, despite my best efforts, a certain opacity persists and I cannot make myself fully accountable to you, is this ethical failure? Is there in this affirmation of partial transparency a possibility for acknowledging a relationality that binds me more deeply to language and to you than I previously knew? (2005, p. 40)

Act Four: The Analytic & Synthetic

Theorizing may occur anywhere, with concerns arising out of one's personal life story, professional knowledge, or from a problematic residing in our culture. It may grow "all at once" out of a mixture of any or all of these factors. Vague patterns may occur, patterns of new possible relationships. A great deal of fusing, stewing, imaginative leaping, and insightful juxtaposing of elements takes place. Gradually the beginning of order emerges – a perceived clarity of relevant variables to consider, the existence of generative value that informs and directs the development, the dynamic relationships that bind the pattern.

(MacDonald, 1982, p. 59)

...living one's life well requires a type of restlessness, an interpretive alertness to the possibility that things could be understood otherwise than we have come safely to assume.

(Jardine, LaGrange, & Everest, 1998, p. 129)

...scholarly discourses, even scientific ones, must be situated in human affairs and discourse, and that the "meeting-place" for this complex cacophony is "conversation."

(Pinar, 2004, p. 193)

Reflecting Upon the Process

After several unsuccessful attempts to weld my results together into such a whole, I realized that I should never succeed. The best that I could write would never be more than philosophical remarks; my thoughts were soon crippled if I tried to force them on in any single direction against their natural inclination.— And this was, of course, connected with the very nature of the investigation. For this compels us to travel over a wide field of thought criss-cross in every direction.—The philosophical remarks...are, as it were, a number of sketches of landscapes that were made in the course of these long and involved journeyings.

(Wittgenstein, 1953, p. ix)

Throughout Act III, I tried to keep my analytic distance. I wanted to (mostly) evoke (some of) the moments that have occurred during my journey towards a critique, or at least a deeper understanding, of the prevailing notions of health literacy as both patient and parent, without burdening the participant (reader or audience-member) overmuch with theoretical discussion and analysis. Instead, I hoped to capture the feelings, frustrations, and insanities of the experiences and the evolutions that this process has rained down upon my life. Taken only as a series of events in a life, it would suffice to say that a great deal has happened over the seven-plus years chronicled, perhaps more than one might think of as normal. What could be viewed as series of challenges and unfortunate occurrences can also be viewed as an enormously rich and diverse health literacy curriculum, in that the

various experiences, readings, and reflections have given the opportunity to unpack the notion of ‘health literacy’ on numerous levels and in a multitude of incarnations.

In this Act, my purpose is to analyse both the process and content of Act III (and what it can tell us about the possibilities of health literacy as a policy, public health and clinical notion), as well as demonstrate the practice of critical health literate analysis of cultural artefacts, something I have learned to do over the course of this project. In doing so, I hope to illustrate a number of key ideas about health literacy, especially what might be entailed in any notion of a ‘critical health literacy’.

Embarking upon an exegetical dissection of Act III is, of course, problematic: after all, the critical interpretation of the ‘text’ of Act III by the *writer* and *experiencer* of said Act is ripe for accusations of delusions of grandeur, lack of depth and breadth in the analysis, or merely the hubris of the postmodern moment. I agree that all are possible. Mykhalovskiy (1996) points out that academic gate-keeping, in the form of naming a writer’s work as self-involved or self-indulgent is “peculiarly silencing” (p. 135). However, the purpose of this exploration of the idea and reality(ies) of health literacy is *not* to have someone else evaluate and comment upon this work as an ‘observer’ (in anthropological parlance), thereby creating a case study, or life history, or ethnography; rather, the intent is for the actual person living and writing these experiences to step back and critically, *reflexively* (to use the academic) contemplate the events, reactions, words, *et al.*, as something more akin to a ‘participant-observer’ (again, to borrow anthropology’s vernacular), especially through the process of ‘coming to understand’ the concept and how it scaffolds through time. Van Maanen suggested that perhaps this process is “best reformulated in hermeneutic terms: a dialectic between experience and interpretation” (Van

Maanen, 1988, p. 93). It is certainly autobiographical: however, it also morphs into auto/ethnography at the point at which I begin to reflect upon the individual within the social (and speaking as the individual in question).

‘Health literacy’, the central idea of this work, is taking on a significant, and still expanding, role in the world of professional health care and health policy: it is certainly being talked about and attempts are being made to ‘operationalise’ the concept, as the literature review in Act II illustrated. Whether it’s understood within the lens of health promotion, health education, public health, clinical practice or policy, health literacy is essentially understood as the outcome of an *act*: whether that act is reading, asking, scheduling, maintaining, dosing, attending, consuming, *not* consuming, changing, initiating, or any number of other *behaviours*. The impetus of the act must be derived from somewhere: health literacy seeks to make what is extrinsic, intrinsic. In other words, there is a push to create a need, and even more importantly, an unquestioning desire, to engage in the act as defined by the external source. The challenge is captured well in Charles et al.’s observation about the history of medical necessity:

[It] can be seen as a history of conflict over meanings and attempts by various groups to gain public support for their particular view and for the “facts” that they claim about it...[and] meanings can be used to “create associations that lend legitimacy and attract support to a course of action” (as cited in Stone, 1988, p. 121). Whoever gains control over the definition of a particular problem will likely be the one to set the policy agenda for its resolution. (Charles, Lomas, Giacomini, Bhatia, & Vincent, 1997, p. 386)

To deem someone 'literate' means at least two things: the first is that there is a state of *non-literacy*; the second is that there is someone *who is already deemed literate* judging the status of the other – or, in this specific instance, 'setting the policy agenda for *health* problem's resolution' (the problem is illiteracy – the resolution is the literacy program). Within such a framework it becomes clear that there is an expectation that is fundamentally tied to notions of education (which is not to say *formal* education). In order to be literate, there needs to be some body of knowledge that is deemed important enough to be in possession of, and there must be someone who is in a position to share, in some manner, that knowledge. In education there are different terms in use, such as curriculum, teaching and learning, but regardless of the terminology, the essence remains the same. There is a quintessential transfer of *something* taking place.

Health *literacy*, then, is something that is something that must have a *content base* (also called knowledge or curriculum), it must have those who already have some grasp of and belief in that content base and can serve as the *teacher*, and then there must also be those that act as the *learners*, or those that are perceived to be in a position to benefit from this knowledge (though whether the 'learners' agree with such an assessment often remains to be seen). Within this particular set of relationships is also the kernel of power: the power to define the content, the role of teacher, and the identity of the learner.

To date, the research and writing around health literacy has been the purview of those delineating the *knowledge*, and those serving as *teachers* (and these are sometimes, though not always, the same individuals). They have identified the *learner*, and they have increasingly made a point of talking to the learners in order to understand how they might design interventions that bring the learners closer to their (the teachers' and knowledge

holders') perception of 'health literacy'. No one, it seems, has looked at what it means for a 'learner' to be in the process of 'becoming' health literate: in other words, no one has looked at the health literacy *currere*, to borrow Pinar's notion (2004).

Pinar (2004) states "*currere* seeks to understand the contribution academic studies makes to one's understanding of his or her life" (p. 36). I believe that it is possible (and even necessary) to extend Pinar's idea to encompass non-academic, yet still educational, moments in one's life. Although he does acknowledge that "academic knowledge is not self-contained, that it often reaches out toward and back from life as human beings live it" (p. 186), this comment is still set within the formal academic encounter. The view that there are myriad sources of influential learning – *both inside and outside the formally academic* – that impact a life opens a sluice gate to the "complicated conversation with oneself" (p. 37) Pinar envisions in an even richer fashion. *Currere* is conceptually very powerful: by the *learner* looking at how the *learning* (formal and informal) has impacted her or his life, it becomes possible to see aspects, intended and unintended, of beliefs held about any number of things, or an "intensified engagement with daily life, not an ironic detachment from it" (p. 37).

Of course, Pinar's work with *currere* is intended to engage educators in both self-reflection (to better understand their own unique experiences and how they contribute to their pedagogical practices) as well as illuminate *how* educational practices might mould lives (beyond the obvious "I learned how to spell 'cat' or add 2+2" sort of endeavours) in the as-yet-unknown future. I am not taking up his concept from this standpoint: rather, I am applying it to notions of health and health literacy, in terms of my experiences and my identity(ies) as patient and parent (past, present and future).

This leads naturally, I believe, to understanding *currere* and auto/ethnography (autoethnography) in many of the same ways. *Currere* takes up the narrative from the standpoint of process or method, a way in which to come to a more holistic understanding of the individual, in and through experiences and analysis of experiences – it is, by its very nature, autobiographical; auto/ethnography goes further, seeking to understand the individual through the social, specifically the individual *researcher* through the socially *researched* (Geertz, 1988). Reed-Danahay describes it thus:

auto/ethnography has a double-sense – referring either to the ethnography of one’s own group or to autobiographical writing that has an ethnographic interest. Thus, either a self (auto) ethnography or an autobiographical (auto) ethnography can be signalled by “autoethnography.” (1997, p. 2)

Not to be trapped in a binary, Reed-Danahay points out (accurately, I think) that this is not really an either-or proposition: the “auto” exists in the “ethnographic” and the “ethnographic” exists in the “auto”. Perhaps it is only a matter of degree or nuance. Within this study, that position has shifted as situations have evolved.

How long does one need to be a part of culture in order to fashion a reasonable autoethnographic account? A year? A decade? Does one need to be born into it? I suppose arguments could be made from a variety of standpoints. Certainly, I can claim that I was born into the Western Canadian/Western medical paradigm or culture, and as such can provide an account of the experience. I was born female and white, so again, I can comment on this perspective. I was born into the middle-class (just barely), so I can bridge some of the distance between differing experiences in working class and middle class.

But what about *autoethnographic accounts* of mothering and health literacy, or of personal illness and health literacy? Eight years ago (2004) I certainly couldn't authentically provide anything relating to mothering and health literacy – I might have engaged in an ethnographic/fieldwork enterprise (and I had most assuredly been an observer in the field for any number of years – observing my mother's interactions with me and health issues, and my grandmothers' interactions, primarily with my parents), and I could definitely provide a cultural critique of the health and mothering messages that proliferated around me, but I could not make connections that were *autobiographical* (and thus fulfilling the 'auto' requirements of 'autoethnography'). Seven years ago I was largely in the same position in regards to health literacy and (personal) illness and injury – I was an ingénue.

However, the transformative moments of becoming a mother (2005) and becoming a long-term patient (2006) essentially re-wrote my identity, and in doing so, initiated me into the cultures of mothering and personal illness and injury 'recovery'– and, inadvertently, into the cultures of surveillance that underwrite much of passes for health care. And these are the same notions that bankroll most notions of health literacy. In these moments, I became authorised to speak on behalf of these sub-cultures, if only thanks to my role (however limited) within a social group.

Permission to write in the auto/ethnographic voice is something that was difficult to give myself: Neumann argues that "autoethnography is a form of critique and resistance...[exploring] contested meanings of self and culture" (1996, p. 191). I have only recently come to the realisation that I am a full-blood member of the cultures that I am

writing about, and as such, I have finally allowed myself to write as a representative of these groups.

While *currere* doesn't require me to have a membership, only to be an individual (thus the autobiographical nature), auto/ethnography insists that some degree of cultural inclusion is a prerequisite. And while I can certainly reflect back to my beginning days as mother, student, patient, and write about them, it is not until further along in the experience – with more “regressive” behind me – that I began to notice an auto/ethnographic voice emerge. What point that is in time remains (forever) to be seen: there is no way to know that ephemeral and elusive moment where I crossed over to full, comprehending membership of mother, patient or PhD student.

What I might have said in 2007 differs enormously from what I have to say in 2013: and that is the challenge in the enterprise of autoethnography. If you are a member of the culture, you will always be a member, to some degree, and as such you will never be able to come to a ‘closure’ that wraps up fieldwork and moves to an office for the report writing. Every day, indeed every moment, provides new fodder, and this inherent aspect is both invigorating and damning.

This is not, however, an auto/ethnographic account of “how difficult it is to be a new mother/patient/student”, though well it could be. It isn't the actual returning to school that has pushed the study in the direction it has taken - not really. It has a great deal more to do with *what* I have found myself studying alongside my role-transformation that has, in fact, had profound influence. I have adopted this approach to my study for one particularly powerful reason: as Reed-Danahay states, “Practitioners of ethnography have become increasingly aware of the politics of representation and of the power relations inherent in

traditional ethnographic accounts” (1997, p. 2). So, while there have been researchers that have looked at some of the aspects of my topic (“becoming health literate”) from the ‘outside’ (as, essentially, ethnographers, though they call themselves clinicians or policy makers), there have been none that have looked at the experiences of health literacy, mothering and illness *autoethnographically*, or from the ‘inside’. And, as such, those “natives” have not told their stories – either about themselves as part of a group, or about their group and its impact on themselves.

Why is this? Is it because this area of inquiry does not require consideration? Given the interest in ‘Health Literacy’ as an area of policy and practice research and writing, this doesn’t seem likely. Is it because the power structures are so well established that those that might consider telling their stories are prevented from doing so, perhaps by being denied access to a means of sharing these stories (Van Maanen, 1988)? If so, the advent of the Internet, blogs and podcasts should shift that power somewhat (voices are certainly being released into cyberspace: it remains to be seen how many ‘experts’, or even fellow laypeople, regard any of these voices as credible or legitimate). Is it because no one has even realised that such a gap exists? Perhaps. Is it because those that *have* realised (if only semi-consciously) that such a gap exists are prohibited by limits of time and energy? Likely.

I find the word ‘gap’ interesting: while ‘gap’ certainly does mean an absence or lack of something, it also means that there is an *opening*, a *space* into which opportunity might find its way. An autoethnographic account of mothering, health literacy, and illness *currere* is one way of responding to this liminal space. Liminality, the state between ‘pre’ and ‘post’, where identity is fractured and yet to be rebuilt, needs to be explored further,

and this study contributes in this manner. This liminality applies equally to the discipline or domain of health literacy, as to how a person might experience health literacy.

Returning to our discussion of *currere*, it is interesting to note that while it doesn't position itself as ethnographic, per se, it has strong ethnographic components. It reflects upon the historical and the social, but it does not set itself the task of being descriptive in any manner other than that that helps bring the *regressive* and the *progressive*, the *analytic* and the *synthetical* into greater focus, and into relationship with one another in a far more concrete fashion. By the same token, auto/ethnography does not charge itself with the partitioning of the *life-as-lived* as the auto/ethnographer in a manner that might suggest method, but it certainly shares the notions of distance and synthesis with *currere*. Each has the potential to positively inform the other.

Finally, a note upon the idea of individualism: Both auto/ethnography (despite its situating the individual within the social) and *currere* focus on singularity. While I do not attempt to speak as anyone else within this work, I have been distracted on more than one occasion by the overlapping, layering and cyclicity of my stories in my parent's, my husband's (of whom I've said very little – though his perspective, in his words, would constitute another whole study), and my children's lives. If they were to tell (many, though not all – hence the singularity) these stories, they would have different perceptions and different reactions. Further, their stories have impacted mine, often before anyone realises it or has a choice, as in parents and children (whether I'm the child or the parent). These stories are centred upon ideas of 'health' and 'health encounters' as a means of investigating 'health literacy', but it is impossible to separate it out from the conditions and

narratives of lives – why we believe what we do and why we react the way we do are only what we catch fleeting glimpses of, as we run by the mirrors in our lives.

Re-Encountering Act III

On the Staging

By employing narrative prose structure within “the performance” of the work (which is to say the ‘data set’), I am hoping to bring readers into the liminal space, where the push and pull of health and the life-as-lived are encountered: Spry calls this the “Performative-I”. This requires a certain abandonment of convention. By switching back and forth between my situated identities, through the artifice of the three staging areas, I am attempting to depict something akin to bricolage (Denzin & Lincoln, 2003; Kincheloe, 2005; Spry, 2006; Steinberg, 2009). I do this to show the tensions experienced and, to some extent, the relentless pursuit of and questioning of those experiences which co-construct the knowledge necessary to bring a critical perspective to the idea of health literacy in the *life-as-lived*.

It is impossible to capture every moment of a life, or of a body’s and mind’s experiences, as Butler (2005) points out. It has never been my intention to itemise my experiences: I have most assuredly left pieces out, not because they weren’t important, or were too painful for me to share, but because I have already, through another vignette, captured the essence. In some ways, I employ the same strategy a grounded theorist utilises: I am looking for the saturation point, the point at which I’ve picked out all of the possible instances of ‘health literacy’ at play in the given data pool. For instance, I didn’t write about hoof-and-mouth disease, umbilical hernia surgery (other than to mention it), medication reactions, stitches, concussions, ear tubes, projectile vomiting, or ambulance

rides. I didn't talk about conversations I had with my mother around aluminium toxicity, or discussions I had with my father-in-law about cough medicine, or debates my husband and I held over the true nature of organic foods. They're all interesting, and I could have, but at some point a limit must be reached.

Choosing to speak in a monologue (with limited off-stage voiceovers) was also a clear choice: the entire concept has been to allow one person to speak of her health and wellness experiences as they play through a period of her life. The casual and conversational vernacular steps outside the prescribed voice of academia, the stagehand continually bringing more material onto the stage, and the usage of signs to mark and contextualise the various segments, are all attempts to both break the 4th wall concept of theatre in a Brechtian fashion, as well as open up a more intimate space for the reader/audience to encounter these experiences.

The staging (three spaces) and the props served additional purposes. The setting aside of a clinical space (with its own lighting array) was certainly meant to delineate those events that were explicitly medical, but you'll note that every time the narrator moved into this space, she donned a gown. This was to signal a notion best captured by Young (1989):

Clothes are the insignia of the social self. Their removal separates the body from its social accoutrements. This reduction of the social self along with the enhancement of the medical realm completes the dislodgement of the self. What remains is the dispirited, unpersoned or dehumanized body. (p. 159)

So, by adopting the convention of signalling the 'unpersoned' self through the hospital gown, I am trying to capture the sense of dissociation that repeated hospitalisations engenders.

The stagehand bringing in additional props as the scenes progress is intended to reflect the ever-increasing volume of reading, information, accounts, and so forth, that have been spawned by the experiences and ‘education’ contained in this study. Literacy allows for an expanding horizon of texts to be available, and this both complicates and enriches all future literacy encounters. By allowing the narrator to use the props at will (to sit on, rifle through, move), I hope to symbolically signal the incorporation of the material into a life-as-lived. There are times, as the narrator, when the material gets in the way: this, too, is symbolic. I would be very interested to see how an actor working with the text, but not necessarily the experience, would undertake a performance of this piece.

The ‘character’ is, of course, my voice: I am comfortable in adopting Reed-Danahay’s definition of “autoethnography...as a form of self-narrative that places the self within a social context...It is both a method and a text” (1997, p. 9). It would have been impossible to *only* touch on the health moments in the scripting; as an auto/ethnographic form of writing, it is pivotal that a world is crafted around the character – the subtleties that define a place and a time, and, by default, a worldview. I move between narrating the recent past, the distant past, and the stream-of-consciousness narration, interrupting the normal conventions of storytelling and staging, giving the auto/ethnographic voice fluidity (cf. Humphreys, 2005).

I elected to keep my academic observations to a minimum during Act III. While there a few moments where I felt compelled to cross over and become explicitly theoretical, far more I chose to ‘park’ my observations for analysis here, in Act IV. There are a few reasons for this: first, I wanted the voice to remain authentic throughout Act III; second, it was important to me to keep the narrative flow moving forward, and while I

could envision ways to amalgamate the theoretical with the performative, the flow would be sacrificed; third, I wanted to use an alternative space (Act IV), one distanced from Act III, to contemplate what I had written, especially to pull out the analysis of the evolving health literacy potentials it portrays.

Of course, throughout this process I have been reflecting, and what I have experienced and learnt has operated reflexively upon my writing. By this, I mean that the person I was when I began writing, editing and re-writing, is different than this person that is ultimately going to hand over the ‘final’ copy with which the world will engage. Short of including all of my successive drafts in one copy (similar to what Critical Theorists of the Frankfurt Schools were known to do (Willinsky, 2007)), it is in my analysis that I can expose my progression.

Nothing in this study is pure: nothing has been captured at the exact moment of its birth, untainted by those things that transgress upon life, such as language, expectation, or perception. Everything is filtered. That does not necessarily make it bad: in fact, such sifting is a useful technique, when reflected upon, that illuminates how we are moulded and conditioned by culture. In this sense, it allows for a Freirean encounter with my critical health literacy experiences. I was cognisant of moments, as I moved through the writing, of my view and perception expanding and contracting, being re-formed in front of and behind me. This is also apparent, I feel, in the narrative: my character voice is far more engaged in a ‘critical’ health literacy later in the text, than at the beginning.

Finally, inasmuch as the intention has been to engage in an exploration of the emergence of awareness of health literacy, especially something that might be conceived of as a ‘critical’ health literacy, there has been – always – a secondary motive. This work

(especially Act III) is a chronicle of the emergence of a person that is, ultimately, the mother of two small children. I am, irrevocably and unrepentantly, their mother and their primary educator. What I have lived, and who I am becoming, will forever be inscribed on their identities as much as mine, and I owe them this account. By engaging in a critical way with the story I have shared, I open possibilities for them, for understanding and interacting with the world, in their own time.

On scene i, 1974 – 1982: The Really, Really Deep Past

There is an impossibility to such a beginning: to capture effectively the pivotal moments of a life's commencement in only a few (hopefully) well-chosen words, especially when that life is your own, is no mean task. Really, this work starts *in media res* and, as an auto/ethnographic work, it can be no other way.

It is readily apparent that I have had, before any of the other scenes come into play, an inordinate amount of Western biomedical experience as a child. I paid attention, I asked questions, and I had parents who would (mostly) answer these questions. Building my repertoire for a health literacy that was diverse (though still circumscribed by the scientific model), through circumstances beyond my control, has been an unmitigated success, as far as my own mothering and future patienthood have been concerned. I draw upon these texts of identity (Shotter & Gergen, 1989) every day of my life, consciously and unconsciously, and it is certainly possible that this is how I ultimately came to be interested in the topics of this study.

I find it intriguing, as well, how I have framed my experiences of hospitalisation (as a child) as largely positive, yet I struggle now, as a mother, with the idea that *my* children might find such separation, under similar circumstances, anything but terrifying and cause

for future abandonment issues. I fully recognise that, circumstantially, my mother had little choice in how this situation played out: she was as much a product of the isolation of motherhood when families are displaced from their original communities as many, including myself, and her personal supportive resources were extremely limited. Twenty years later, when I became a paediatric ward volunteer (when considering paediatric medicine as a career), my role was largely to operate as a source of comfort for children whose mothers were *in absentia*. Unreflective as I was at that time, I certainly recall feeling superior, being able to comfort these poor children whose mothers weren't there (regardless of circumstance). I am now ashamed of myself, the sort of shame that only maturity can confer.

Despite this, this scene was enjoyable to write: re-reading the passages that so captivated me as a child, despite the dilapidated condition of the books (too much love, and a dearth of book binding tape) was refreshing. These World Book volumes are certainly dated, and there are obvious gaps in the knowledge (by today's standards), but they still serve their purpose of general orientation quite well. The body hasn't changed a whole lot in thirty years, it seems, nor have the basic norms of talking about and aiding the ill and injured.

I can see in these pages the framework for my thinking about the body: partitioned by anatomical geography (the ankle, the shin, the knee), and then by symptom (itching, burning, pain), I am instantly returned to the Spinal Clinic. The world described in these books is the same one the doctor asked me about: "No, I asked you about your *pain*" (not your burning, twitching, etc.). The framework is unchanged (and I suppose it would be a bit worrisome to find out it had, in truth).

As well, looking over those sickness layettes, I must laugh: the precisely lain safety pins, gauzes, and bandages, all in a sterile field (i.e. a clean white towel) might be pencil drawings of the same sort of arrangement I now produce for my children. In fact, as I write this, arranged upon my dresser you will find (on the requisite clean white cloth) ibuprofen, acetaminophen, ear drops, cotton wool, throat lozenges, a water glass with a straw, and a pinch bowl of salt (for gargling), because today (November 20, 2013) my eldest has once again been diagnosed with scarlet fever. His amoxicillin is in the fridge, and the oral syringe is sitting on the counter, air-drying, after being washed in warm, soapy water. We have notified all relevant parties who may have been exposed. It is a pitch-perfect rendition of “care of a sick person in the home” health literacy.

Interestingly, though this is framed in the regressive moment, there is something of the progressive in it, too: for, while I recognise my actions in the books I read as a youth, I also recognise my mother’s self-same behaviours with *me* when I was sick. My father still counsels salt-water gargling. I can imagine a future where my sons set up the same protocol for their children, not because there is some external source of ‘knowledge’ that advises it, but because it was done for *them* in their time of need. Is this, then, ‘health literacy’, or is it cultural health beliefs, or something else we haven’t quite put our finger on? Is it ‘health literacy’ when it’s the *correct* course of action, in the scientific framework, but something different (which may or may not be illiteracy) when it isn’t the authorised version?

On scene ii, 1982 – 2004: Before

As I hit the ‘fast-forward’, I skipped ahead to my early twenties, a time when I still fancied a future in medicine. There were a number of reasons for this fantasy, not the least

of which being the status conferred upon me should I achieve this end. I didn't read about infectious disease for this reason, however: no, I really and truly did (and still do) find health and wellness matters fascinating (but far more the social construction, than the biological components, I have some to appreciate). I say 'health and wellness', but at the time it would have been 'medicine' or 'public health', because I did not yet know about medical anthropology or rhetoric or symbolic anthropology or human geography or any of these ideas that I encountered in my first post-secondary school experience.

Upon the realisation that there were, in fact, alternative modes of thinking about health and wellness in the world (that extended beyond my enchantment with *National Geographic*), I began to get the slightest hint that maybe there was more to the world than I had first assumed. Works like Emily Martin's *The Woman in the Body* (1987) and Geertz's "Thick description" (1973/2003) played a fundamental role in shifting my perspective – avowedly prairie-white, working class, nondenominational (but still quasi-Christian) until this point – to something a bit broader, a bit more receptive.

Here also is the contrastive moment in my relationship with information. Like many of my generation (though arguably not after me), I recall the advent of email and the Internet: as a young adult, and in university, I was introduced to the fledgling efforts of the university's IT services. Research reports were carried out in the library. Photocopiers and worktables abounded. A constant supply of pocket change was critical. The idea of connecting people and ideas across the world was limited to the telephone or lettermail. And the mostly painful reality looking back? If I was attempting to prepare a PhD thesis twenty years ago, given my life circumstances, I would simply have not been able to do so. Which begs the question: How many perfectly capable individuals (in my particular

instance, women with small children, medical issues, and little support) have been denied educational opportunities because of systemic limitations? I don't imagine that the line-up is especially long, but it is still a loss.

And then I feel guilty: I work in comparative luxury. I sit in my home, my children nearby, and information is magically delivered to my Internet oracle. Even hard-to-retrieve articles from the past are sourced and delivered to my inbox by diligent library personnel. Perhaps I have not suffered enough in order to complete a thesis. Nonetheless, these early experiences with formal *currere* and self-guided education made a deep impression upon me, that I didn't really begin to see until I looked back through this study.

On scene iii, 2004 December – 2005 September 1: Transition to 'Now'

There are really three distinct moments in this scene: pregnancy, delivery, and freshly-minted motherhood. I chose to link them all together, in part to reinforce the overwhelming nature of the experience – it was literally one thing on top of another within a relatively brief time. My 'learning curve', in terms of the authorised pregnancy, delivery and mothering discourses, felt frequently just about vertical, despite the copious amounts of reading I had undertaken beforehand (Calgary Health Region, 2004; Dorling Kindersley Limited, 1999; Hogg & Blau, 2001; Leach, 2003; Murkoff & Mazel, 2008; Murkoff, Mazel, Eisenberg, & Hathaway, 2003; Spock & Needlman, 2004; Weissbluth, 2003)¹⁷.

First, a bit about the Diclectin/Gravol debate. My paranoia was especially home-grown: my father has many times proselytised about my mother's impending sainthood for enduring her pregnancy with me, primarily because she refused to take *anything whatsoever* for epic NVP. I was probably the only five-year-old in my community who

¹⁷ The 2008 version of Murkoff & Mazel's work is the replacement copy I purchased when my second son was born.

could pronounce ‘thalidomide’. After the tragedies that befell Canadian (and other countries’) children during the brief Golden Era of thalidomide usage (Schwarcz, 2001, pp. 25-29), there was no way my parents were going to endanger their first-born. Of course, without this background, I would have still been highly concerned; it’s just that *with* it I became hyperaware and hypervigilant. In fact, if my parents ever see or hear this piece, it will be then that they discover my Gravol usage, and there will be an accounting.

I find it interesting that, despite my education and experience (and, ostensibly, my ‘health literacy’ around the relationships between risk, NVP medication and pregnancy), the issue of Gravol has been such a harbinger of guilt. Realistically, I did my homework, and I did speak to a medical professional prior to ingesting even one tab, yet that *formative* health literacy imparted to me by my parents (and our prairie culture of the 1970s) still seems to define my perceptions and evaluations, even circa 2013. Yes, I did take the Gravol, and thank God I did – I had already torn abdominals, something that led to the umbilical herniation, and something that I didn’t have repaired for seven years. But I will probably go to my grave regretting the decision, for no other reason than the knowledge that I put myself before my child.

It has been pointed out to me that, in my discussion around the Brewer Diet in this scene, I talk about fats but I don’t talk about the carbohydrates, and those are probably what led me to my 225 lb. peak weight and gestational diabetes diagnosis during this time. As well, the contrast in the pregnancy diet for Jack versus the pregnancy diet for Noah couldn’t be much further apart. With Jack I simply ate what made me feel better (as per the Brewer Diet), which included eggs, cheese, yogurt, milk, lean cuts of meat, fruits and vegetables (and a lot of toast); with Noah, I had clinical ‘beverages’ that had precise

amounts of proteins and carbohydrates, alongside a medium-chain triglyceride (MCT) liquid supplement for fat. Interestingly, I was gestationally diabetic for both (and noticeably much sooner with Noah, despite my awareness and dietary precautions).

I have thought a great deal about this point since it was made, and I have wondered at what it says about my clinical health literacy in this particular situation: for instance, was I health literate to search out a pregnancy diet that (while still healthy) promoted more dairy-based fats, and made it possible for me to decrease (some of) the NVP? Did I overeat carbohydrates during this period (perhaps, though I certainly don't recall this)? I still gained a large amount of weight with Noah, despite the very precise math involved in my diet during his gestation, and I certainly was not overeating. In fact, the high-risk ob/gyn was baffled by my weight gain in light of my diet at the time. I was 'health literate' insofar as my medical condition and the diet required for its management was concerned. What part does my unique metabolism combined with two very different pregnancies have to play in this particular set of events? Every single one of my specialist team members in my second pregnancy felt that diet was key to managing the situation, and avoiding the outcomes (including weight gain, gestational diabetes, and pancreatitis) experienced with Jack. And despite the fact that I followed the prevailing wisdom to the word, the outcome was virtually identical (right down to the hospitalisation for pancreatitis ~8 months post partum with both children). Does 'health literacy' even have a place in such a bizarre set of circumstances?

Returning to the scene, the Diabetes in Pregnancy (Jack's pregnancy) clinic incident still smarts. True, I was treated with insulin, and true, I recognise that due diligence is required by medical staff: however, I wonder at the situation where there is no room in

clinical evaluation for an assessment of the health literacy of the patient, in respect to her physical condition, and her prior knowledge. Because insulin is a pharmaceutically-controlled substance in Canada (rightly so) I need a prescription, which means I need a diagnosis. And further, given both the prevalence of undiagnosed and/or untreated diabetes worldwide (International Diabetes Federation, 2012), and the maternal complications untreated gestational diabetes produces (Dain, 2011), I should count my lucky stars.

In my mind, given my clinical history, my suboptimal tolerance levels, and the very real risks to the baby, and further given the definition of gestational diabetes as “any degree of glucose intolerance with onset or first recognition during pregnancy” (American Diabetes Association, 2004, p. S88), I met all of the guidelines for treatment. The Calgary Health Region has a two-step protocol, an initial screening (the part I’d endured), and a second, full OGTT (Oral Glucose Tolerance Test) with those registering as suboptimal (Calgary Health Region, 2002), to confirm diagnosis before treatment.

If I’m being honest (and I, insofar as such a project can ever be ‘honest’, *am* being honest), then I must tell you that that last paragraph is entirely new information to me, new at the time I was working reflectively with the scene, despite its availability during the time period in question. There are at least two reasons that this is the case: the first (with respect to the diagnosis and care guidelines from the American Diabetes Association) is that I didn’t know to even search for such information – in other words, the knowledge I had to date was, to my mind, full and sufficient. Since this time (nearly eight years ago) I have become increasingly skilled at identifying what I might have to consider further, and where I might have to search for that information, and increasingly my go-to is the Internet (with all kinds of caveats, of course). The second reason, with respect to the Calgary Health

Region handout I was given as part of my Diabetes in Pregnancy folder, is that I either didn't read carefully, or didn't understand what I read. I suspect it's the former. Regardless, my righteous indignation over the occurrence is not quite as surely footed as I thought when I wrote the scene. It is certainly unsettling to capture a moment in time in a scene, only to revisit it as a 'different' person, temporally and spatially, and discover how much is *not* seen.

The birth story, and the 'health literacy' required of me at the time, speaks for itself: because I chose not to be 'educated' in birthing, I was reliant upon the skills of the delivery team. I don't regret this (which is an interesting realisation), because I'm convinced that there is no way a training class could have prepared me much more than I had prepared myself (panting practice notwithstanding).

As for any sort of 'health literacy' that could have been constructed prior to the actual clinical delivery situation, I'm not sure what I could have done that would have been reasonable. It was certainly harrowing in the pre-birth hours to not fully understand decels (D-Cells) and the side effects of fentanyl, and I was barely keeping up with the clinical talk swirling around me. I realise that health practitioners have a specialised lexicon for their work, especially in fast-paced environments such as delivery rooms or emergency rooms. Of course I want them to be able to understand each other – it's just that my husband and I were sitting *right there* and they were talking *about* me, not *to* me. And as soon as they descend into the jargon of the profession, it gets scary for the patient and their family. A bit of situational sensitivity might go a long ways (and yes, I could have asked, I suppose), and here we see a form of 'health literacy' that falls more on the side of the practitioner than the patient.

Post-birth breastfeeding practice was challenging. It is a terrible feeling to want to and expect to feed your baby, and not succeed. I had called the La Leche league prior delivery, wondering how they worked with mothers who were having difficulties with their milk coming in (anticipating, correctly, my own challenge), and the woman I spoke with informed me that “all mothers can nurse; some just don’t try hard enough.” So, as I sat there, knowing milk wasn’t coming in no matter how hard Jack and I tried, this was at the back of my mind. My ‘breastfeeding’ health literacy was supposed to be enough to make my physical self learn and perform as per requirements.

I have often wondered at the audacity society has when it comes to mothers, especially new mothers. People have touched me, touched my baby, given unsolicited advice, asked extremely personal questions, and browbeaten me, the Costco Woman and formula incident being the most severe (and surreal) in my life. It is hard to overstate the malevolence with which some that breastfeed treat those who don’t or can’t breastfeed. Consider these words, the third posting in a series incited by an online article on Disney’s ‘Babble’ blog *Is breast really best? Are the benefits of breastfeeding exaggerated?* (Wolf, 2011):

Based on this one article, I wouldn't reccomend [sic] your poison to any child bearing woman! This is the most horrible disgusting crap I've ever read. Granted there are a few circumstances which [sic] may inhibit a mothers [sic] ability to breastfeed, and for those women formula may be a godsend. However for the majority of American women who choose formula because they are simply too damn selfish and lazy, YOU are the puke of this nation giving those women a piss poor excuse. If you don't want to breastfeed because you don't wish to sacrifice

your time, sleep, career, or the appearance of your breasts... Ten [sic] don't have a child! Being a mother requires sacrifice... If you can't sacrifice yourself for you [sic] own child's health for monetary reasons, that's your prerogative. But this lady implying that breast in NOT best does not excuse your selfishness as a woman and a mother. (Marian Theresa, response posted February 26, 2011)

The vitriol is palpable, and it is not uncommon. The responses to Wolf's well-balanced article run for another *forty-one pages*. And while I appreciate both the freedom people should have to express their opinions in an open forum, and that there is something for everyone to learn in encountering the other with an open mind, there is a wide distance between respectful dialogue and such venom. These anti-formula discourses (and that is a very academic, polite way to put it) were and are omnipresent, and they interfere with mothers (new ones, especially) from being able to engage in thoughtful, balanced contemplation of information, and thereby make an informed, arguably 'health literate' decision for themselves and their family.

On scene iv, 2006 April 25 – , Learning to be 'Patient'

Sontag's much-quoted opening lines to *Illness as Metaphor* make sense in a way I wouldn't have appreciated eight years ago:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, 1977/1988, p. 3)

In many ways, her words are almost all I want to say about this section of this work. But there is something additional I know about her words: they were written when she was suffering from cancer, and not even once during this most-famous of her works does she tell that truth about herself. While I appreciate (and use) her theorising, I resent that she did not make that a part of her writing. It is fundamental to understanding the depth of her perception. Maybe her discipline prohibited it, maybe her personality forbade it, or maybe, like I am finding now, it is incredibly hard to talk about one's mortality, especially when there is clear and present danger. Regardless, how much more profound are her observations when contextualised within her own battle with mortality? How much more 'health literate' can she be regarded as, given her reality?

This is, of course the moment of the biographical disruption Bury (1982) speaks of – having a child was an interruption, of sorts, but it was one I wanted and anticipated, and for which I was ready. This, however, was the 'big one'. Frank (1991) has captured my experience perfectly, and I live with its truth:

When I become ill again, and someday I will, I hope it will not be the total break in my life, the radical discontinuity, that I experienced before. Health and illness are not so different. In the best moments of my illnesses I have been most whole. In the worst moments of my health I am sick. Where should I live? Health and illness, wellness and sickness perpetually alternate as foreground and background. Each exists only because of the other and can only alternate with its other. There is not rest in either word. In "health" there can only be fear of illness, and in "illness" there is only discontent at not being healthy. In recovery I seek not health but a word that has no opposite, a word that just is, in itself. (p. 135)

There is, in this kind of health literacy, something that only emerges when faced with these moments that set into relief a self that is ‘healthy’ with a self that is ‘not healthy’. It is also into this liminal space that ideas of ‘healing’ creep, where the awareness that comes from the disruption can rend the two selves apart, leaving a place where one may or may not eventually heal (which is not the same as a return to a place of ‘before’).

My copy of Frank’s *At the Will of the Body: Reflections on Illness* (1991) and *The Wounded Storyteller* (1995) were the very first books about life with illness that I ever picked up. They are now tattered, dog-eared, much underlined, and deeply loved. They offered me a form of intellectual consolation in times when my mind worked, but my body refused to. When I discovered that Frank lived and worked in my city, at my University, I did the thing I never do: I reached out, only to say how much his work meant to me. He was most gracious in his response, and I am grateful.

I can now look back and see that his mode of being, “Quest Story”, is at play in my life. He says

Quest stories tell of searching for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges. The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking. (Frank, 1995, p. 117)

This process is, of course, known by other terms in the larger academic world: the recursive is the reflexive, the journey is the continual hermeneutic horizon, the liminal space is that which opens up between the regressive and the progressive within *currere*. The ill person, within the cultural contexts of illness and healthcare is the auto/ethnographic; the analysis of the interplay of the two is my critical health literacy. It

is all here, in this quest that I have (inadvertently) embarked upon. Without this disruption's categorical imperative, I would have continued obliviously. But *because* of this moment in my life, I have had to search for new ways of being, and new modes of understanding for myself (and perhaps, for others). Whether that constitutes healing, or not, remains to be seen.

On scene v, 2007 August – A Lesson in Mortification

I would like to pretend that I realised how profound and apt the title of this scene was when I chose it: it certainly *felt* right, but I emphatically had *not* considered the two meanings of the word 'mortification', and what they might say about me and my behaviour in this scene. The first meaning, of course, is shame or guilt; the second, however, has to do with subduing the impulses of the flesh, as in overcoming your physical self. Both apply to what happened here.

I am still not sure what to make of this scene: yes, I wrote it tongue-in-cheek, as a blackly humorous take on a decidedly unfunny moment. But there is far more there than that. I have to ask a few questions when I revisit it, the first and biggest being "Why?" I had every resource available to seek first aid and medical help. I even had an in-vehicle telephone. Yet I chose to *crawl* on the boulevard rather than obtain assistance. I wouldn't even take support from my husband. Was it the knowledge that not much could be done? Was it the humiliation of being so incapacitated by a *pinched nerve* (of all the ridiculous things)? Was it the shame of being 'responsible' for what has just happened to me? Was it my working class upbringing that instilled in me the sense of fierce independence? Was it my inherent belief that it *had* get better soon?

Further, why didn't my husband (on any of his numerous times checking upon me) recognise the severity of the situation, and our collective inability to deal with what was obviously an emergency. This thought hadn't occurred to me until just recently. There are four possibilities that come immediately to mind (and some, none or all might be right). First, it might have never dawned on him that he might call for help; second, perhaps he was worried about how I'd react if he did; third, maybe he was recalling his own mother, many years prior, and her ruptured disc, and how it was dealt with at home; fourth, it's possible that he was afraid of me going back into the hospital. I guess that it's also feasible that he didn't think it was really that bad, or conceivably he was embarrassed, too. The mortification might have been mutual.

Something even deeper lies unspoken, and it is tied (in this scene) to my perceptions of the connection between my current state (lying on the curb) and my *responsibility* for finding myself lying on the curb. In my mind (though, I must note, not in that moment's reality), I was *fat*, and therefore not healthy, and as a result my back had decided to exact fitting punishment. This is the insidious underside of the idea of health literacy: It's the difference between eating fruits and vegetables (is it 10 per day still, or has that changed again?) and having an extra helping of sausage because it tastes so damn good. So, while the 'knowledge' one possesses might speak of one way to be 'healthy', the reality of one's body and soul might prescribe another. As if one's *intention* is to be regarded by the general population as 'fat' (recognising that our current cultural norms and expectations around body shape are just that – current). "If only you *wanted* to be lighter, you'd eat less, exercise more..." Except so very much of this concept of agency is tied to

far more than individual onus. This is part of the danger that health literacy engenders: ‘you’re empowered now – so what’s your problem?’

Most commonly, the rhetoric of fat (at least in our 21st century Western disquisition) seems to be associated with notions of weight and activity. Much of health promotion’s health education campaigns are dedicated to making sure we all know how much we ought to weigh and how much we ought to exercise. I am ‘health literate’: I can tell you the correct answers. But I’m overweight and I don’t get much exercise, so maybe I’m *not* health literate. Because, by extrapolation, if I *didn’t want to be in pain* (and lying on the curb), then I should exercise and lose weight. Maybe it’s like being ‘literate’ and reading only trash: do you read trash because a) it’s all you’re aware of, b) it’s all you have access to, c) it’s way easier to digest, or d) it feels good. If my answer is c) or d), am I ‘literate’ or not? If I *can* do something, and I don’t (or don’t want to) where does the idea of ‘literacy’ live then? When things go ‘wrong’, where does the blame lie? (I thought it lay on the curb).

All of this analysis notwithstanding, I’ve come to believe that there was something even more powerful at play at that particular moment: the previous year I had spent a considerable amount of time in the ICU recovering from pancreatitis. For the following year, I had been in and out of the hospital for appointments, consultations, tests, and the like, both to understand and control my condition, and to determine whether we could have another baby. I had spent an inordinate amount of time away from my little boy (not even two years old yet), and I was facing questions of disease and mortality every single day. In short, I was afraid.

The next two weeks might have been avoided (maybe) if I been aware enough to realise what was going on: but the thought of separation from my son was more than I was able to bear. The last time I had no choice: this time I did, and I wasn't prepared to once again have my son watch me carted away in an ambulance, and have my husband wondering just how much more he was going to have to shoulder.

On scene vi, 2007 December – 2008 March: Mistaken Identity

This scene is an interesting contrast for me: I was entering a sacred, 'other' space, one for which I was not, technically, authorised admittance. Frank (1991) believes that

...hospitals and other special places we have constructed for critically ill persons have created the illusion that by sealing off the ill person from those who are healthy, we can also seal off the illness in that ill person's life. (p. 6)

This sort of compartmentalisation may have the benefit of allowing specialised functions to occur in specific areas, but anyone who has suffered a serious illness, particularly long term, can tell you that you simply cannot compartmentalise your identity in such a fashion. Nonetheless, I felt the fraud: while I was certainly 'ill', I was not 'that kind of ill'. I had hypertriglyceridemia, not cancer, and my presence on the unit felt like a usurpation of others' identity. My situation was, at least in the immediate moment, nowhere near as dire. I felt like an imposter, collecting on sympathy I had no right to claim, because not only was I walking through the main hallway towards the treatment areas as a patient (in some form), but I was doing so while visibly pregnant. There seems to be an especial pity reserved for ill pregnant women.

However, after the entrance depicted in this scene, the walk through the main foyer at the Cancer Centre, I moved into a completely different world. Once I was sitting in the

nutritionist's office, the conversation became very intense. I was certainly an active participant, because I understood not just the terms of treatment in discussion, but also the *implications*. It is one thing to know the abstract; it is entirely different to appreciate the concrete (for instance, a tunnelling catheter placed when awake offers a unique experience and form of knowledge not available elsewhere).

I remember being very clinical during that discussion. My outward affect was probably a bit creepy for them, though they never indicated anything. By now I was learning (through the *currence* of medical experience) the lingo, the behaviour, the systemic negotiations required to get the best outcome for my body, and my baby. I was prepared to do whatever that required, no matter that I was already becoming aware of those sorts of things a critical theory perspective afforded. I was noticing the differences in access, opportunity, treatment, the contradictions and hypocrisies, but I was not prepared to take social action and thereby potentially deny myself, and especially my baby, the fullest assistance possible in this medicalised environment.

I was also trying out various illness identities at this time: I was “attempt[ing] to reconstitute and repair ruptures between the body, self, and world by linking-up and interpreting aspects of biography in order to realign present and past and self with society” (Williams, 1984, p. 197). In this iteration, I was “composing [an] impression” of myself (Riessman, 1990, p. 1195) as clinically competent, health literate, and logical (Lupton, 1997). This identity was at odds with other identities that fought for space: the hysterical, the confused, the depressed, the overwhelmed or the needy. But such a “public account” of myself was “grounded in the need...to claim legitimacy in the eyes of the other” (Radley & Billig, 1996, p. 230). Already I was showing signs of developing a method of presentation

of self (Goffman, 1959) that would enable the maximum benefit to play back into (especially) my family's life: this is perhaps the most critical of the 'critical health literacies'. I had no idea, as yet, what I was doing – self-reflexivity was still in the *progressive* moment.

**On scene vii, 2008 March, Easter Monday: The Myth of Freedom of
Information, Protection of Privacy, and Informed Consent**

Freedom of Information, Protection of Privacy and Informed Consent are noble ideas, and well worth pursuing. However, anyone who has been in an Emergency Room triage area, including the examination 'rooms', knows that it is a façade: practitioners talk to one another loudly, sometimes over distances, linen curtains separate the exam areas, and are constantly swishing to and fro as an array of personnel enter and exit these fabric bubbles. For those facilities with actual exam rooms (and the glass-walled pocket doors that are now in vogue), the doors are rarely fully closed, because so much traffic is constantly in and out. Anything, and I mean *anything*, that transpires between the individuals contained within is common fodder for anyone in the vicinity, and even further, dependent on hearing. In the age of smartphones, this should terrify us all (and let's face it – people *don't* shut off their devices like the signs say).

There is perhaps no clearer way to assess the communication skills of clinicians and technicians, or the health literacy skills of the patients and their companions, than spending a large amount of time lying on a bed or stretcher in the ER or Urgent Care, just listening. A great deal can be learnt from what is said (or not), and *how* it is said. I might not know people's name or home addresses, but I can certainly tell you a few things, some very intimate things, about these people around me. I suppose the rationale is that we don't see

each other's faces: but that is iffy. Consider the previous four hours you all just spent in the waiting room, with little to do but stare at the wall, each other, or (increasingly) our smart devices. Consider the swishing curtains and partially open doors. Consider the possibility of being released at the same time (or transported at the same time).

So, this day, I had this awful experience where I witnessed this woman's indignity, at least aurally. I still feel sick when I think about it: the utter crassness with which she was treated by those that she turned to for help. At no point was an interpreter called (and our metropolitan hospital has interpreters in dozens of languages). Judging by the accents used, I believe that an interpreter would have been readily available. Because she couldn't use the language, and therefore answer the questions (and also probably because she was in distress), she was unable to play an active role in her (and her baby's) care. Her husband's absence, necessitated by the hospital admittance obligations of all patients (ie. paperwork), only compounded the situation. My husband has had to do the same for me many, many times, but at no point (barring two) could I not speak for myself. And I held the dominant language.

This woman was pregnant, alone, in pain, didn't speak the language, and was brown (I was able to briefly see her at times when the curtains moved): for all I know, she was a brilliant scientist in her home land, or a gifted artist, or grade school teacher— my point is, in this circumstance she was cast as effectively illiterate and discernibly *lesser*. And the approach to such 'illiteracy'? Speak louder. And angrier. That will definitely make the obstinate, uncooperative, noncompliant patient instantly understand a foreign language.

By the same token, Informed Consent presupposes a capacity, or *literacy*, around the health matter at issue. In the above instance, it is unlikely that the patient gave consent, let alone *informed* consent, to be examined (though the argument can certainly be made that presentation at the ER is tantamount to consent, at least for examination, if not treatment). I have been in more than one situation where I didn't have the capacity to give consent, and the reasons have been diverse: too much distress to process the information, lack of adequate information, and lack of adequate background have all come into play. Yet it is impossible, especially in those ER moments, to say, "please bring me my computer" or "is there another physician I can consult with" in order to give truly informed consent. It is merely a legality meant to protect the practitioner, and not the patient.

On scene viii, 2008 March: Playing the Odds, or the Home Stretch

The "predetermined and preestablished discourse" that Freire & Macedo speak of (1987, p. 55) binds the doctor into the discourse of the remission model that Frank identifies (1995), and it also expects that the patient be bound likewise. Getting better, through compliance, is the general expectation. Compliance requires a certain kind of 'health literacy'. Getting better is equivalent with the alleviation of symptoms. Contextual factors that may exacerbate the problem (whatever it might be) are at odds with this model. It seems preferable to release an asymptomatic patient than it does to maintain hospital care (in this case), even if the calculable risk indicates that almost immediate re-admission is likely. This 'contextual' discourse competes for space with the dominant discourse. While Freire & Macedo envision an "emancipatory literacy", they recognise that "if emancipatory literacy calls for the celebration of one's discourse, you will inevitably have competing discourses, all with the same goal in mind" (1987, p. 54). This is true in this scenario: the

remission ('get better, get out') discourse that dominates the exchange and indeed the entire medical model is conflicted with the contextual discourse ('get out, get sick') reality. Which discourse, then, more accurately reflects a 'health literate' discourse?

I find it interesting that I chose to cope with the events of that time in my life by writing narrative 'letters': this one is particularly powerful, because it was written while I was sitting in my hospital bed, staring oftentimes out the door at the nurse's station as I searched for words or contemplated my next rhetorical move. It captures precisely what I was experiencing, with very little 'lag' (though the omnipresent 'narrative editor' was always there). Additionally, the physician was aware I was writing about our interactions, I am quite sure. He would have to have been completely daft to miss the fact that I was often looking at him in the hallway as I wrote (he was frequently at the nurse's station), and he would barely be backing out my door when I would ferociously resume my typing after one of our 'rounds'. I have often wondered in the passing years how he felt to be the one documented, rather than the typical balance of the relationship (was he charting that I was an obsessive personality, with my never-ending writing? did my writing indicate I was 'well'? I wish charts were shared freely) (Charon, 2005). Was he unnerved? Did he suspect what I was writing? I will never know. However, I think it is interesting that never once during my 2 ½ week sojourn in that room, leading to Noah's birth, did this doctor ask about what I was writing, or why. I had crates of books and articles, a laptop and notebook beside me at all times, and a perceptible focus, and only the nurses ever engaged me on the topic. Why was this? Isn't at least part the physician's job to know something of the patient (beyond the numbers on the chart and the physical affects) in order to treat them, or even more, to help them heal? It is easy to declare that he lacked the 'narrative

competence' that Charon advocates for practicing physicians (Charon, 2001; 2004; 2006; Charon & Montello, 2002). By the same token, I knew nothing of him, and there was never a moment where the door opened for that to change. I think we both lost something, and while treatment may have occurred on some level, healing was never part of our relationship. Would we be right to call this health literacy or health illiteracy, or something entirely different?

On scene ix, 2008 June – 2009 May: Mommy OT & ContraBand

Despite the lengths I went to during this period of time with Noah's head shape, he still sports diagonal asymmetry – something I face when I attempt to purchase him sunglasses. I end up having to purchase ones that can be heated and moulded to his cranium (and ear level), and that equates to more expensive sunglasses. What five year old that you know (barring a Hilton or Kardashian) has Ray-Ban Wayfarers? Ridiculous. You might even think that sunglasses for children are absurd, or you might even go so far as to declare sunglasses to be for sissies (as certain of our family hold). However, I trust our optometrist's advice (despite her patent fashion insanity) about the long-term damage that sun can cause, and so I do subscribe to sunglass science.

I was startled, when reading a document on *EthnoMed*, to find that certain Asian cultures find a slightly flattened back of the head attractive (Graham, 1996). I had thought that a rounded head would be a universally appealing feature. Apparently not. Further investigation took me to an interview with Dr Peter Fleming, professor of infant health at Bristol University, responding to concerns from the public about the drastic increase in flattened heads as a result of what we, in North America, call the 'Back to Sleep' program. Defending the program's success rate (a 70% lowering in the incidence of cot/crib death at

the time of publication), he remarked, "I do not think it is a medical problem - it is more of a cosmetic one. Mothers may feel it is a syndrome and a problem when it really is nonsense" (Carter, 2003). This claim, I found, is supported by relatively recent research coming out of the University Hospital Maastricht in the Netherlands (Govaert, Michels, Colla, & van der Hulst, 2008).

I have to admit three things happened when I read this (just today): first, I was ticked off. That "mothers may feel" something that "really is nonsense" (whether it's true or not) smacks of the patronising tone many (particularly older male) physicians take with 'Mothers'. To, out of hand, attribute the belief to mothers as a group, and then to essentially strike down their concerns with a linguistic sleight of hand is unbecoming at best, and condescending at worst.

The second reaction I had was sheepishness. I *did* think that there were less-than-ideal outcomes (that were *not* merely cosmetic) at hand if I took no action. In fact, I clearly remember being told that my son could suffer balance and coordination issue that could lead to developmental challenges (there are, admittedly, a lot of 'coulds' there). While I wasn't entirely clear on the process, I remember it being attributed to sound reception and eye tracking, commensurate with his degree of deformational plagiocephaly.

So my third reaction was to dig deeper (yes, five years after the fact). It seems that there *is* a body of evidence indicating that there is the potential for developmental problems in children with untreated deformational plagiocephaly (Collett, Breiger, King, Cunningham, & Speltz, 2005; Siatkowski, et al., 2005). Ultimately, the unreflective choice I made initially around the course of treatment for our son's cranial imbalance, seems to fall within the 'no harm no foul' category.

What is particularly interesting about this whole set of reactions and observations is this: the information I accessed around my responses (especially the pros versus cons of developmental problems) is *not* readily available to any interested party. All of this information is contained within journal articles in scholarly publications (not that they even agree with one another). So, in the absence of either a) a definitive diagnostic direction (which is to say the researcher/experts *agree* on something), or b) a cultural reason to *not* desire a rounded head shape, a parent seems best to pursue treatment with a moulding orthosis. At least his head will be more or less attractive in his native culture.

On scene x, 2009 March: Pox Parties & Vaccination Wars

I really, really struggle with the concept of intentionally infecting a child. I know that even my phraseology in this last sentence begs for rejoinder: it has been pointed out to me that “intentionally” infecting your child is precisely what immunisation is, and it has also be noted (and bluntly, at that) that *not* “infecting” your child by immunisation is tantamount to allowing *uncontrolled* infection of your child (the greater evil). Both arguments are couched in a certain sort of ‘health literacy’, inasmuch as both purport to be scientifically-based and verifiable. And each loathes the other.

I have tried to examine all of the opinions/evidence: abortive tissue used in the testing of vaccinations, the use of mercury, the use of other preservatives, the supposed link to autism (Specter, 2009), the suppression of the natural immune system (M. Schmolke, personal communication, 2009), you name it. I have also read extensively about the history of disease and vaccines, including the original patent applications, the anti-vaccinationist campaigns (Allen, 2007), and the histories of many epidemics and

pandemics (Leavitt, 1996; Iezzoni, 1999), including ones that can now be mitigated by vaccines (Cartwright & Biddiss, 1972/2000; Sipress, 2010).

No less than the Vatican has weighed in on this matter: In June 2005, the Vatican issued a statement and summary to one Debra L. Vinnedge of Largo, Florida, in response to a letter from her group, Children of God for Life, regarding the moral stance the Vatican takes on vaccines developed from aborted foetal tissue. The document states:

As regards the diseases against which there are no alternative vaccines which are available and ethically acceptable, it is right to abstain from using these vaccines if it can be done without causing children, and indirectly the population as a whole, to undergo significant risks to their health. However, if the latter are exposed to considerable dangers to their health, vaccines with moral problems pertaining to them may also be used on a temporary basis. The moral reason is that the duty to avoid *passive material cooperation* is not obligatory if there is grave inconvenience. Moreover, we find, in such a case, *a proportional reason*, in order to accept the use of these vaccines in the presence of the danger of favouring the spread of the pathological agent, due to the lack of vaccination of children. This is particularly true in the case of vaccination against German measles.

In any case, there remains a moral duty to continue to fight and to employ every lawful means in order to make life difficult for the pharmaceutical industries which act unscrupulously and unethically. However, the burden of this important battle cannot and must not fall on innocent children and on the health situation of the population - especially with regard to pregnant women. (Pontificia Academia pro Vita, 2005)

This document's presence on the *Immunization Action Coalition's* is interesting, as I'm relatively certain that Ms. Vinnedge had no intention of *supporting* immunisations when she wrote for the Vatican's stance. Visit the *Children of God for Life* website (www.cogforlife.org) only if you have a very strong stomach.

Moral arguments and visual rhetoric aside, how is a parent to actually *decide* what to do with immunisation? And further, what role does social sanctioning (or not) have in this matter? Wherein does 'health literacy' lie? I don't know: I just know that in the final analysis, I cannot condone imperiling my son's health, and I believe the stronger argument comes down, finally, on the side of vaccination generally. Problem is, if that changes, I cannot take back my actions. As Shakespeare said (c. 1600), "Therein lies the rub". And as Mooney & Kirschenbaum say (c. 2009)

The vaccine-autism advocates are scientifically incorrect; there's little doubt of that at this point. But whether they could be called "ignorant" or "scientifically illiterate" is less clear. After all, they've probably done far more independent research about a scientific topic that interests and affects them than most Americans have. (p. 15)

So, despite advocate's research and understandings of the 'evidence', Mooney & Kirschenbaum avow that these individuals are *still* health illiterate. It becomes clear here that health literacy may mean 'coming to the right conclusion' as determined by those who know 'more' (or at least claim to). This is a very perilous position for any definition.

On scene xi, 2009 October – 2009 November: To the Edge of Sanity

At the time depicted in this scene, my husband and I were hesitant about influenza vaccinations. I had been researching my dissertation for long enough to have developed a

healthy cynicism towards believing what I was told by the media and authorities, and the further I had read into the history of public health, medicine, power, feminism, and mothering theory, the more uncertain I became. I was certainly attaining something called “critical” health literacy, so much so that I couldn’t actually make a decision. The ambivalence imparted in the ‘critical’ that I’d read so much about amounted to the word ‘crippled’ in practice.

Unlike the passage I’ve crafted above in response to the preceding scene, and despite the fact that I’ve come down once again on the side of vaccinations, don’t be fooled. I have never been as scared as I was those months in 2009. To have all of this occur on the heels of having my child vaccinated was terrifying. Simply put, my thoughts were “What have I done?” I had, with no hesitation, taken him to his 4 ½ year appointment, yet a few weeks later, in the face of the threat of an H₁N₁ pandemic, I hesitated. Why?

The reading around critical literacy I had been undertaking had made me suspicious, and when mothers in Jack’s preschool debated the relative merits (amid admittedly mass confusion), I sensed enough uncertainty in myself to delay. Not because I believed them, and not because I was doing independent research that pointed me towards non-vaccination (such as the ‘information’ contained on Dr Mercola’s www.mercola.com or the National Vaccine Information Center’s website, www.nvic.org), but because I was increasingly aware of how little I did know, and how unlikely any decision I was to make constituted an informed one or, by extension, a health literate one. And Jack got sick. Of course, it’s possible he’d have gotten sick regardless; I suppose it’s also possible he could have had an adverse reaction to the vaccination. My point is only that there is a fine

(indiscernible) line between critical health literacy being useful, and it being deadly. *And no one knows where that line is.*

On scene xii, 2010 February: Multi-Tasking Mommy

I wanted to depict a more-or-less ‘typical day’ in my life: the realities of mothering, health care, feeding, clothing, entertaining, transporting. Nothing dramatic: just a set of steps leading to a structured medical experience (this time with a dermatology specialist), with my smallest child. I hadn’t suspected when we went to this appointment that I would be turned back towards myself and my family’s heritage (not that it was a problem – it was just a bit of a surprise). I noticed in analysing this scene that I didn’t feel threatened in this situation, and I’m not sure if I should chalk it up to the demeanour of the physician or the newness of the medical research (which allowed me to avoid losing face for being uninformed). Perhaps I simply cut myself some slack.

I had noticed a pattern in my transactions with medical professionals when my children were around, and I was a bit disturbed to look back at Illich (1976/2002) and read these words:

The child learns to be exposed to technicians who, in his [sic] presence, use a foreign language in which they make judgements about his [sic] body; he [sic] learns that his [sic] body may be invaded by strangers for reasons they alone know; and he [sic] is made to feel proud to live in a country where social security pays for such a medical initiation into the reality of life. (p. 112)

For as much as I appreciate Illich’s point, I have to ask: what choice does someone have if he or she wants access to the system? And does such acceptance of “medical initiation into the reality of life” have anything to do with ‘health literacy’?

As much as I would like to suggest that Illich's perspective in 1976 bears no resemblance to the world I live in 40 years later, I can't. I have both witnessed and experienced Illich's annexation of the body for medical purposes. My tactic, admitting that I *do* seek and value Western medical care for my children, is to try and be informed before we attend, to explain everything in terms my children can understand, to ask questions on their behalf (and to coach them in asking their own questions) and in modelling how to behave and ask for different accommodation if needed (temperature, touch, privacy, and so forth). This is, perhaps, a very privileged, Western way of regarding and reacting to such a situation, but it is nonetheless the path I take.

On scene xiii, 2010 February, Continued: A Trip to the Grocers

When I found the following passage recently, I was delighted: *Finally*, I thought, *someone who understands me!*

If your curious George plays with a phthalate-ridden plastic toy at someone else's house, or drinks a jug of flavoured milk, he is not likely to perish on contact. (Just think of all the things we were exposed to as kids, in the age of Better Living Through Chemistry).

We do all of the above, because we want what's best for our kids, and we want them to be thoughtful, earth-loving adults one day. They needn't be people who require several hours to buy soap or beans because they are so paralyzed by the details of every buying decision. Arm your wee ones with the knowledge to make good decisions for themselves and the planet, and set a good example for them by undertaking all of the green behaviours you want for them, yourself. (Smith, 2012, p. 79)

But when I wrote the original ‘Trip to the Grocers’ scene, I was *not* in this headspace. Again, all of the reading, writing, and reflecting I had been doing had me in a tailspin. Perhaps this is why I have found Pinar’s *currere* so intriguing: I have been able to chart my evolution through education through this study, and I have seen very clearly how I have been pushed and pulled, turned inside out, as new ideas from all corners came at me, largely through my own invitation (and the stacks of books and papers on the stage are getting very tall by about now).

My primary concern (and reading topic) at this time was food, and the concomitant concern with issues of chemical additives, either in the growing or the processing stage: after Jack’s illnesses in 2009-10, I was deeply conflicted about nutrition’s effect on Jack’s health. Having grown up in an agricultural and food processing based community, I had a pretty good idea about how food was produced in the commercial-industrial complex. From crop spraying to pig barns to feedlots to slaughterhouses to food processing plants, I had seen a lot, and right from childhood. I hadn’t really given it any thought: it was just the way the world was. But then I started reading about food – its place in our lives, its histories, how it has evolved (or devolved, if you ask some) over the past 100 years, especially. Once I started reading, I couldn’t stop: starting with Upton Sinclair’s *The Jungle* (1906), I then discovered Michael Pollan’s work, especially *The Omnivore’s Dilemma* (2006), *In Defense of Food* (2008), and *Food Rules* (2009). I read through Margaret Visser’s work (1986, 1991), Barbara Kingsolver’s *Animal, Vegetable, Miracle* (2007), Ann Vileisis’ *Kitchen Literacy* (2008), Sandor Ellix Katz’ *The Revolution Will Not Be Microwaved* (2006), Mark Bittman’s *Food Matters* (2009), Warren Belascos’ *Food:*

The Key Concepts (2008). Of course, once you start down a road considering food and farming, you end up at Wendell Berry's doorstep (2009) every single time.

At the same time, I was hitting the Internet pretty hard: from Dr Mercola to the USDA, and absolutely everything in between, I read and followed trails. I learned a great deal, and for a while I was almost religiously fanatical about food purity and the 100-mile diet. I even denied myself my beloved mayonnaise, because it wasn't organic (or more precisely, the organic version wasn't nearly as good as the conventional kind).

But then I started to pay more attention to the world around me, especially the experiences of those in other parts of the world, and I came to realise that my righteousness was indicative of my privilege. Masses of people go to bed hungry every night, and hundreds of thousands die (especially children) of malnutrition every year, and we're going on about organic and the devil that is Monsanto? If seeds can be engineered to grow faster, larger, and be disease resistant and adapted to drought conditions, what right do we have to say that impoverished people should turn them down? Of course, the whole issue is a lot more complicated than I am presenting right now, but it should give you a flavour for the competing texts in my mind.

Nowadays, we still try to be sensible, and support local growers and producers: crackers from 4000 miles away are hardly justifiable, and strawberries in December are probably not a great idea. But a sense of balance has begun to pervade my decisions, thankfully. I am still uncertain as to whether this newfound equipoise constitutes health literacy, health illiteracy, or merely a 'make-do' proposition. Again, arguments come down on all sides.

On scene xiv, 2011 May: The Prolapse Files

At the back of my mind, while I was sitting listening to the assistant massacre the handout, I kept flashing back to something I'd read at the very beginning of this study. Here it is: Referring back to the American Medical Association's 1999 report on health literacy, it stated

Even though simple materials may increase appeal and satisfaction, they may not be understood by individuals who have very limited literacy. Thus, important questions include (1) What is the best way to communicate medical information to patients? (2) What is the minimum content required for patients to achieve their self-management goals and what is the literacy demand of the task(s) we are asking the patient to carry out? (3) Can visual aids, videotapes, and multimedia technologies improve patients' understanding of medical information and can they do more effectively than simplified written materials? (4) How should clinicians approach decision making with patients who do not understand informed consent? (5) What is the most cost-effective way to enhance compliance when patients have poor health literacy? ...Importantly, researchers and providers must involve patients – the real experts on health literacy—in developing and testing interventions. (p. 555)

So, if my health region was attempting to advocate some form of health literacy through the 'reading' of the handout to me, and if we take the AMA's recommendations as having merit (both of which I do) then there was a discernible gap between the two philosophies (or, at least, models).

In returning home, and after writing this scene, I dug out the AMA's article, and wrote a draft reflection on the scene. I looked at (1) What is the best way to communicate information to patients? Well, evidently handouts written in 'clear language' or 'plain English' were most desirable (though it is exceedingly difficult, I'd say, to get past the obsession with, and occasional necessity of, medical jargon), and likely to be viewed as most efficient and cost-effective to the *system*. You just need someone to develop (and proof) the handout, and away to the photocopier you go. Now, it is debatable as to whether, pedagogically, this is the best way for *patients* to receive information (and thus support 'health literacy'). Having a sheet of paper read to you is hardly innovative. And let's not forget that, although you are supposed to be able to ask questions once you're read the sheet, there is the clear, bold proviso on the top, which states: "If you have any questions or concerns, please call your doctor." How are we, or the nurses, suppose to know which questions we're allowed to ask (and have answered) in this 'health literacy' encounter, and which must be moved up the food chain?

Then I reviewed (2) What is the minimum content required for patients to achieve their self-management goals and what is the literacy demand of the task(s) we are asking the patient to carry out? Well, beyond the clinical terminology, the discharge instructions had very basic 'keep clean, keep hydrated, keep moving' suggestions. This, one may argue, is sufficiently informative for the majority of post-operative handouts where no especial wound-care, physiotherapy or drug/diet regimens are required. Provided, of course, that patients are at least minimally conversant in the language presented, and allowing that they share similar ideas about surgeries and aftercare (both of which are perhaps presumptuous).

As far as the ‘literacy demands’ they (the system) are asking of me, apparently listening for understanding and asking timely questions are paramount, and obviously, as this is a handout, the ability to re-read it for clarification at a later point is required. So, speaking, reading, and understanding spoken English are necessary, as are the numeracy skills required for noting the passage of time (which is more of a cultural frame of reference, than anything), and the proper dosing of pain medication (after all, “There is usually little pain after surgery. Any discomfort can be controlled with medicine such as acetaminophen or ibuprofen”. Woe betide those that (a) have pain, and (b) can’t control their ‘discomfort’ with over-the-counter medications. Back into the system you go). There is also the numeracy requirement of understanding what a weight of 4.5 kg (10 lbs.) feels like so as to avoid lifting (and how to measure it, perhaps) and knowing how to measure temperature for a fever (above 38 degrees Celsius or 100.4 degrees Fahrenheit). These are all assumed skills within this context. Nothing and no one checks for these understandings, because either a) people are sensitive to being seen as treating someone as stupid, or b) the assumption is that this information is so *simple*, so *commonsensical* that it never occurs to anyone to ask the question(s) (A. Montgomery, personal communication, November 14, 2013).

The next point, (3) Can visual aids, videotapes, and multimedia technologies improve patients’ understanding of medical information and can they do more effectively than simplified written materials?, seems to be self-evident, at least in terms of what is made available to the patient post-surgery. I have a stack of surgical after-care, hospitalisation discharge, and public health encounter handouts, and not one reference to a multimedia, visual or other form of curricular (because that’s what these things are,

wouldn't you agree?) intervention. All are printed, word-and-numeracy-based resources. I have no way of knowing whether this is because there hasn't been any intervention testing and evaluation done, or whether testing *was* done and proved ineffective or inconclusive, or whether it was done, but it proved too costly in terms of time, money, or other resources for implementation in the Health Region.

When I read (4), How should clinicians approach decision making with patients who do not understand informed consent?, I was troubled. One thing that has always struck me is that the push for informed consent assumes the rightness of the thing one needs to be adequately informed of so that they can (of course!) give their consent. For instance, turning down treatment in cases where one is assumed to live or die as a result of action or inaction, taking the route that leads to (almost certain) death is considered to be (at least in my culture) an indication that you are *not* of sound mind. Many times people will do whatever is in their power to convince you that you *should* undergo x, y, or z, because it will make your life better or longer. You can say 'no', but be prepared that harassment is often the upshot.

So, by the logic of informed consent, I should have had the right to *decline* being read to: I did not give my consent. Ah, but that's not how the game is played. Protocol trumps consent. And by the same token, when I am in the midst of a pancreatic attack or a rough labour, and they produce the paperwork for informed consent for the administration of contrast media or epidurals, how 'informed' I am is questionable. It's quite easy to get people to agree to something when you promise them that agreeing will lead to the pain stopping. But, in all fairness, because clinical encounters are frequently filled with

emergent situations, it is impossible to inform everybody of everything that *might* happen, at a time when their logical faculties are intact.

Oh, but number 5): this one is the most telling, the most provocative. Listen to it again: 5) What is the most cost-effective way to enhance compliance when patients have poor health literacy? I almost don't know where to start on this one. I'll start by paraphrasing it: What is the cheapest way to make sure people do what they're told to do when they don't understand what they're being told? Or maybe, What is the stingiest method of making people do what's good for them even if they're not educated enough to know the difference? I'm not sure what I find most offensive: the presumption of the beneficence and accuracy of the current medical system, the righteousness of 'enhancing compliance', or the supposition that that *noncompliance* is indicative of 'poor health literacy'. Despite the beneficence of offering aid to people who are in need (with need being a contestable notion), there is a very fine line between helping those with 'poor health literacy' (the presumption being that these individuals simply do not know how to help themselves when left to their own devices) and crossing over into an area of coercion, dominance, and tyranny.

On scene xv, 2011 June: Back for More

In this situation, the 'expert' opinion was to remove the offending organ (this time deemed the gall bladder, rather than the historically offending pancreas). Gall bladders are far more common criminals, it turns out, than pancreases. Frank (1995), in examining Parsons' 'sick role' theory, sums up the medical expectation of a 'sick person', thus:

The problem of sickness from this functionalist perspective is how to give people sufficient time to recover without producing dropouts. Exemption must be

granted, but it must also be regulated. The physician is explicitly a social control agent. For Parsons, one of the most important aspects of the physician's performance is refusing to "collude" with the patient; medical sympathy is to be limited by the overriding message that the sick person's task is to get well and return to normal obligations of work and family. The physician is there not to pander but to prod, gently but firmly. (p. 82)

This "restitution story" (p. 83) *expects* a patient to become 'better', at the same time as it *expects* medical society to facilitate this process. This expectation governs the manner in which the system works, both within itself, and in interaction with those with whom it comes into contact. Rarity does not align with a restitution story, and therefore it does not support the dominant discourse. Foucault recognised the double-bind in which I found myself, one that required me to behave a certain way in order to get what I 'needed', but in behaving in that way I was reaffirming the dominance of the health care system (Foucault, 1982), and the positional power of the physician, something I ultimately found untenable.

In the face of a variety of unsavoury options, and a complete lack of information with perspective (the only viewpoint I was offered was this surgeon's 'expert' opinion, which was based on about three minutes contact with me, and a complete dismissal of my prior history), I chose instead to leave, to deny myself "salvation through science" (Illich, 1976/2002, p. 113). I exercised a form of empowerment – the right to refuse treatment. This situation is particularly interesting, because it is both a critical health literacy moment, and an acknowledgement that I believed I was functionally illiterate when it came to making an informed choice about surgical intervention. The medical perspective, which was made abundantly clear once I declared my intent, was that my refusing treatment was

indicative of my lack of clinical health literacy, or compliance with the ‘agreed upon’ tack of my treatment (though, as I have already problematised, it is debatable as to whether it was ‘informed’).

On scene xvi, 2011 November – 2012 March: Epiphany

I’m not sure that my father will speak to me after reading this. My audacity in committing very personal family matters to public paper is an abomination. And as I haven’t ‘interviewed’ anyone involved, I am extrapolating from experience and perspective. Ironically (or fortuitously, I suppose) this time period coincided with my reading of Illich’s *Limits to Medicine – Medical Nemesis: The Expropriation of Health* (1976/2002). This book is another of the small set that have earned a place of esteem on my shelf. I lack the interpretive context to fully appreciate the world he wrote of c. 1975, other than to know through my parents what the world of medicine and healthcare was like.

However, despite this shortcoming, I was still profoundly moved by what he wrote. In essence, his argument is that medicalised-technologised health care robs people of their humanity insofar as suffering is concerned. He writes, “In an insidious way [the doctor] provides each citizen at the last hour with an encounter with society’s deadening dream of infinite power” (pp. 98-99). It is that “salvation through science” (p. 113) that my father sought. His intrinsic belief in the power of medical science cast everyone else’s actions (or lack thereof) into the role of the infidel. Or maybe I have it completely wrong: perhaps it is that, to take no action at all is tantamount to leaving a loved one for dead. Or maybe it is both – perhaps if you try long and hard enough, things will ‘work out’. Regardless, this is not something we are permitted to speak of in my family.

I struggled with these ideas: Illich's philosophies at this moment in my life cast me adrift. After having spent so very much time considering the ideas of health literacy in and around all of the methodological, theoretical, interpretive, political and narrative aspects, and being no closer to understanding (instead, being rather further away), I was reaching numbness. Trying to consider my own theoretical mortality was one thing; facing the very real mortality of someone close to me was more than I was able to process through any of the frameworks I had established. It took quite a long time for me to be able to crystallise this into words, and to be able to move forward in my work. It opened up an entirely new perspective to questions of what constituted health literacy.

On scene xvii, 2012 January: Coming Undone

I'm glad I wrote this scene at the time it occurred: otherwise, I'm pretty sure I would have chickened out, or the internal narrative editor would have had a heyday with the red pen. Even going back through it for the purpose of analysis is tough (and leaving it in the final edit), because I was raised to be very modest (though my personality might make you doubt that statement). In fact, about two weeks ago (mid-November, 2013) I had an entire conversation with my grandmother (who is in a nursing home, and is the same 90-year-old I reference early in this work) revolving around how she did not want a male nurse's assistant, and while we talked around the issue in progressively tighter circles, her most forthright comment was "well, you know, your privates are your *privates*" - and even this was a shockingly intimate comment (and she has never been a shrinking violet, I assure you). But part of the impetus for me to write of this event and the thoughts I grappled with is not doubt thanks to the reading across feminism I have done in this study (Belenky, Clinchy, Goldberger, & Tarule, 1997; Gilligan, 1982; hooks, 2000; Lather, 1991; The

Boston Women's Health Book Collective, 2011; Weedon, 1987). I have been trying to challenge my preconceptions and behavioural taken-for-granted, and this area required attention. That, and too infrequently women are not authorised to speak in such stark terms about things that are (often) taboo. Shame, confusion, and fear are the natural result.

In trying to reclaim my body from a series of increasingly invasive manoeuvres, I have been trying to compose a strong female identity that can undergo such physical intrusions without allowing it to become psychological as well. Having what seemed to be a failed surgery meant that I was not forevermore broken, but rather the mechanic had missed something in the repair work. By researching and piecing together information on my own, and taking the initiative to book an appointment, I felt empowered. I was leveraging my resources and taking informed action on behalf of my health, and I wanted to depict this, no matter the personal nature of the event. This, as you know, did not work out quite the way I'd imagined, something I will speak to in a few more pages.

On scene xviii, 2012 January: There is No 'Worm' in Ringworm

I realise that, in the grand scheme of things, this event is inconsequential. So what if I didn't know that 'ringworm' wasn't a worm? However, like Harris and his concerto experience (1993, pp. 58-59), I recognised the legitimacy of the discourse, and even more importantly, its relevance to my child. Unlike when I was travelling overseas, and was faced with a medical situation where I used my resources to piece together an understanding, and where I didn't feel as if I had to already know everything, this engendered an entirely other feeling. I felt wholly illiterate, and because this particular exchange was related to the health and wellness of my child, and especially because I *thought* I knew what was going on, I also felt as if my maternal practice was shoddy. I felt

ashamed, and I wanted to hide this from everyone, including my husband. So, while I exhibited all of the right reactions, and convincingly so, I was masking my true mind-set.

My psychological reaction is, of course, completely out of proportion with the matter. This is one of a mere handful of similar events in my adult mother/patient life, but it makes me reflect upon how others might feel when faced with similar scenarios. If I am at Nutbeam's critical health literacy level (sometimes I am, other times not) and I have a Level 5 literacy score on the IALS, and I have *this* reaction, is it possible that others with fewer easily accessible (or accessible at all) resources feel like this frequently when in medical encounters? Or is my reaction exacerbated by the health literate identity I've imagined for myself? While clinical health literacy proponents advocate methods like 'Ask Me 3' in order to clarify with (and make additional teaching points with) patients, I wonder how many physicians, in particular in a general practice situation, engage in this with patients they've consciously or unconsciously labelled as health literate? There is certainly no health literacy screening practice in place, other than the informed judgement of physicians, in my home practice (of 20+ physicians). Should there be? Am I an outlier? Does everyone else shrug off these moments? All I know is that be illiterate is an awful feeling.

On scene xix, 2012 February: This is the Last Time (Again)

In writing this, I used the medical lexicon, e.g. 'push', 'fluids', 'port', 'flow', 'cannula', 'site', and 'sliding clamp'. All of these terms and their uses I have picked up in my myriad personal clinical experiences, and because I learned them under very stressful circumstances, my maternal practice cum health literacy seems intent upon forcing me to teach them to my children *now*. There are, of course, at least two other reasons I did this:

the first is that I am displaying my knowledge for the purpose of the affirmation I receive for being an informed (that is to say, ‘health literate’) patient; the second is that it is scary to walk into a room and see someone you love looking like the Borg (my children witnessing my ‘hooked up’ persona).

I loathe this scene. I detest this moment where, after my emphatic (if unrealistic) pronouncements, I was forced to eat crow. It makes me feel guilty that I’m an irresponsible chronic illness sufferer who hasn’t abandoned eating, and who still struggles to exercise regularly. I *know* the health literate (‘compliant’) script chapter and verse, and yet here I am, once again a victim of my body’s betrayal (and my complicity).

To make matters worse, the overlapping ER consults, in all of their negativity, compound my personal regret. The moment I have to make the decision to present at the ER or Urgent Care is the moment all of my bad decisions come crashing down on me, when I realise that there is no more time left to do it better or different. This existential reality is something that doesn’t get calculated into the academic discourse on motivation and agency, or the health literacy measurement tools.

It bothers me still that, because of the medication, I couldn’t formulate a cohesive argument to present to the doctor regarding the when’s, where’s and why’s of my situation. My husband and I often joke that I ought to develop pamphlets or, better yet, a PowerPoint presentation that we simply run when we encounter yet *another* group of health care professionals that have no idea what I’m talking about. That way, I could still speak for myself when I can’t speak for myself, so to speak. Nevertheless, the flippancy that I am treated with in these events (insofar as I, a ‘layperson’ might have a valid and valuable

clinical perspective) grates me, and very likely costs everyone (including the system) a lot more than necessary.

On scene xx, 2012 February: Critical Thinking for Breakfast

The best way to reflect, reflexively, upon this scene, is through yet another vignette: Yesterday (November 2013), shortly after Jack was diagnosed with scarlet fever (for the second time), and as we were waiting for the pharmacist to fill Jack's prescription for antibiotics, Jack hit me up for a beverage from the drugstore's cooler. Normally, I'm not an easy sell, but this time I told him that, provided it wasn't pop or 'vitamin water', I would authorise it – at this point, I was desperate to get him some calories and keep him hydrated. He selected a 'Fuze – with vitamins – Banana Colada'. I didn't really pay close attention, so I was a bit surprised when Jack said, "Mommy, I'm not old enough to drink this." "What?!" was my response.

He points to the side panel where, written in about eight-point font, were the words "Recommended Dose (Ages 12 and Older)". This was followed by the advice, "Drink one 500 mL bottle per day as needed. Do not consume more than 3 bottles per day." (Fuze Beverage, LLC, 2013). As much as I wish I were kidding, I am not. Apparently, 'Fuze' has added vitamins (hence the boldface) in the order of A (beta carotene 1330 mcg 'Provitamin A for the maintenance of good health'), C (120 mg 'Helps the body to metabolize fats and proteins'), E (5.4 mg AT [alpha-tocopherol] 'As an antioxidant for the maintenance of good health'), and B₆ (0.8 mg 'Helps the body to metabolize carbohydrates, fats and proteins').

Presumably, the idea is for the consumer to be drawn to the flashy tropical packaging, and sold by the vitamins – A C E B₆ – listed across the bottom. I have come to

think of such products as nutraceuticals, but it appears that Agriculture Canada would consider this a little more like a functional food (Government of Canada, 2012) with bioactive compounds added or a processed food with added ingredients (an actual category). Either way, it's sugar water with apple juice, milk and cream, and vitamins. Not exactly what I had in mind for my ill child.

Further, the health claims of the various vitamins are, at best, generous. It's not that they're misleading, per se: rather, what average Canadian will look at 'helps metabolize fats and proteins' and know, biochemically, what that *means*? Not many, I'd wager. But what *will* register is something like this: "metabolise – something to do with weight and food and energy; fats – metabolise fats? – that's good, I'm sure – metabolise proteins, huh? – proteins, meat, strength, must be good – and it's Vitamin C – we all know that's good – it's like fruit, helps with colds, doesn't it have something to do with scurvy? Argh, pirates!" And purchase it, on faith that it's 'good for you', and therefore better than the Coke it's sitting beside (they're both manufactured by Coca-Cola, by the way). The values (such as 120 mg) aren't going to have a lot of meaning, either – who carries around the RDA's¹⁸ in his or her back pocket? And this beverage does not have a nutritional panel, so I can't even extrapolate from that.

I suppose I *could* pin Health Canada's *Dietary Reference Intakes – Reference Values for Vitamins* (Health Canada, 2010) to my *Pinterest* health board, or to the front page of my smart phone, for those moments when I need to determine the RDA for Vitamin A for children ages 4-8 (400 mcg), C (25 mg), E (7 mg of AT – alpha-tocopherol

¹⁸ *Recommended Dietary Allowance (RDA)*

only), and B₆ (0.6 mg). Given this, it's pretty easy to see why the 'Recommended Dosage' is 'Ages 12 and Older'.

Two years ago when I taught Jack to read the sides of products he was going to consume, I was certainly take advantage of the 'teachable moments' that Walkerdine & Lucey (1989) so abhor in the middle-class mother, but I don't think it was in pursuit of reproducing the social order. Rather, I am more inclined to think of this event more along the lines of Ruddick's (1989) *protection, nurturance* and *training*. In other words, I was attempting to equip my son with the necessary critical health literacy to make informed choices, by modelling them, and by coaching him, especially when everything around him is designed to make him into a mindless consumer (and despite the fact that, at the time, he was merely six years old). It seems I've been rather more successful with him than I have been with myself.

On scene xxi, 2012 March: The Embarrassing Truth

Like my recent experience with Jack's ringworm infection, this moment was very educational for me. I am both serious and sarcastic with that comment. I am thrown back upon the critical media literacy reading I had done (Brummett, 2008; Giroux, 1997; McLuhan, 1951/2002, 1964/2003; Olson, Finnegan, & Hope, 2008; Sholle, 1995; Sholle & Denski, 1995; Steinberg & Kincheloe, 1995). Insofar as I had attempted to engage with my bodily self-awareness (The Boston Women's Health Book Collective, 2011), alongside a thorough (I thought) review and analysis of the information I had available to me (which included academic papers, professional websites, and personal assessment), I was ridiculously confident about my own self-diagnosis. Of course, I didn't tell my uro-

gynaecologist any of this – I merely prefaced our consultation with the words “I think my prolapses might be back” (notice the “think” and “might”?).

Wrong. Wrong, wrong, wrong, wrong, wrong. Now, whether my wrongness is purely a result of the devil of self-diagnosis, or whether it’s actually a clear indication that I did not fully understand the prognosis of the surgical intervention, I am not sure. For the longest time after this event I was ashamed that I had overstepped my health literacy (so to speak), but recently I have been coming around to a new realisation: in my heart, I had thought that the surgery would *fix* me. I believed that everything would be located, more or less, where it was before having a ten-pound baby naturally, before gaining huge amounts of weight with untreated gestational diabetes, where it was when I was *young*. At no time did the surgeon look me in the eye and say “This surgery does not turn back time” or something equally arresting. Perhaps he felt it was unnecessary to state. Perhaps, as a male, it is simply something he really didn’t ‘get’ – any more than I ‘get’ being male – despite his years of experience and training. Instead of spending my research chips on more fully understanding the outcomes of the surgery, I was more intent on blaming the ‘failed’ surgery rather than the aging body.

On scene xxii, 2012 March: Groundhog Day

This was my first clear experience of metacognition, where I actually felt myself thinking about thinking, and of the hermeneutic pull between the familiar and the strange (Kerdeman, 1998). Of course I’m relatively conscious (and conscientious) when I’m making purchases, especially those that relate to my children, but this was different. It is quite possible that this was the first time (or nearly the first time) that a sort of critical consciousness emerged strongly enough to stop me from proceeding blithely with my day.

I wish I could say that this was enlightening in a refreshing sort of way. Unfortunately, it was the beginning of an exhausting and scary sort of liminality (that is occasionally still very much present) where I am continually evaluating my thoughts and actions (and assumptions) in light of changing information and experience. Certainly we do this everyday of our lives, but the *awareness* and the attempt to document this process and reality have made getting through (supposedly) simple tasks painful (and not just for myself: just ask my husband). I question why it took me so long, from the inception of this study and the experiences (educationally and otherwise) that have framed it, to arrive at this juncture, and I can only speculate that a critical mass must be reached before something passes from the murky depths of one's mind into the full glare of consciousness.

Last week (November 17-23, 2013), when Jack was once again sick with scarlet fever, and was requesting chest rub at nights, I pulled out a bottle of Kalaya, and *instantly* I was back in the moment of time I have captured in this narrative. I suspect this will be the case forevermore. In fact, the chain of consequences that link back and through all of those stacks of books on stage that symbolically represent my increasing 'information' (which is not necessarily the same as 'knowledge') is hard to capture in words. Visitors to my home remark, nearly instantly, about the stacks of books, papers and technology placed *everywhere* (this is not just a device I invented for Act III – it is my reality). Certainly I had a penchant for information from a young age; however, I would argue that this study has exacerbated a longstanding tendency.

On scene xxiii, 2012 July: Don't Wear Tight Shoes

The register that the various medical specialties speak in is part (a large part) of their power. Through this conceptual gatekeeping they protect their dominance. If you use

the vocabulary (correctly, of course) then it's like knowing the password. Shotter & Gergen (1989) observe that

Instead of assuming that people's relations with nature and with society are unaffected by the language within which they are formulated, we find that these very relations are constituted by the ways of talk informing them, by the forms of accountability by which they are, so to speak, kept in good repair. (p. x)

Of course, it's not like they're sitting there saying, "let's manipulate the situation so that this lowly layperson remains unaware of what is occurring and what it all means". Many who become health professionals do so, at least in part, out of a desire to help others. However, whether its systemic, or personal, or part of the professional training, or some other heretofore unknown collection of factors, the reality is that what occurs in the clinical setting, especially the 'specialist' setting, is not meant to empower a person/patient for the most part, and its rather questionable as to whether persons who go in for consultation even register as individuals (and when you have hundreds, if not thousands, in your service, that should be unsurprising).

In this particular scene, beyond the obvious frustrations I experienced as a mother trying to negotiate my own treatment with the need to care for small ones, and the accommodation of the Fellow's learning curve, I struggled to maintain what Goffman (1959) equates with sustaining a self, a reality, a life. I was prone, I had electrodes and needles all over my body, a group of people were standing over me, paying attention to applying successively greater currents of electricity to my body, and watching a computer screen to see how well my nerves withstood the beating (all right, they were actually measuring the conductivity of these nerves in order to determine the state of said nerves,

but still...). I was not me: I was a specimen, and I felt it. It was incredibly important to me, as I look back upon this scene, that I maintain my agency, or at least a *presence* in the room, as a sentient being, capable of engaging in a medical/scholarly discourse about this *body* we were all contemplating.

To their credit, they certainly treated me as such as soon as I began using the proper linguistic framework. Whether I understood or not was irrelevant: I could play a character well enough that I was included in the scene as more than a prop or an extra. But I could not hold onto my identity once I left the room, as is evidenced by the write-up that was provided to my physician. I once again became a set of clinical notes devoid of context, and apparently my shoes were too tight. Despite having every appearance of being ‘interactively health literate’ (and ‘critically health literate’ in the analysis herein), I was still ineffective. These words, in the form of the report, are now contained on my personal record, and even if I were to tell another doctor (who might need this information at a future point) that the person in question in that final paragraph *isn't me*, what do you think the odds are of being believed?

On scene xxiv, 2012 August: There Really is a ‘Worm’ in Hookworm

Here I was obviously attempting to coach and model something akin to ‘consciousness raising’ for my son, alongside my mothering’s ‘training’. It will be years before I have any clear indication of my success. I have been challenged (by his grandparents, on both sides) about my proclivity for sharing such detailed information with my sons, alongside the social complexities that are present in the topics. Their concern, presumably, is that I am placing too much too soon onto their little shoulders. And sometimes I wonder whether they’re right. But here is my even deeper concern: at *what*

age do you start to have important conversations about critical matters with the young? My father oscillated between too much and too little information, dependant upon his comfort level with the topic, but I can unequivocally state that those moments of ‘too much’ information have served me immeasurably well in life, whereas the instances of ‘too little’ information have, in some instances, limited me. I am not critical, not really: I am only observing based on my experiences.

I am reminded of Macedo’s (2006) injunctions against numbing ourselves to the world and its realities through things like ‘entertainment’ and other state-organised events that dissuade us from any legitimate engagement with the world around us. I would be a hypocrite if I was to present myself and my family’s circumstances as anything less than privileged, and it’s rather difficult to ‘unprivilege’ oneself. Yet I am also aware that there is a fledgling sense of instability and uncertainty about the ground we all stand on, one that increases with each day I move through the critical analysis of my experiences and my education (my *currere*) with ideas of health literacy, and I want to impart this questioning to my children as part of my maternal praxis. I am still bound by Warnke’s observation: “The transmission of traditions will always involve a form of power insofar as individuals mature within families and cultures in which the relations of influence between generations are not symmetrical” (1993, p. 94), no matter what I do.

On scene xxv, 2012 October: And the Oscar Goes To...

I chose to write this scene as a play within a play because I had been noticing for quite some time that I was now experiencing health-related events with a fractured perception and something of a fragmented identity. By this, I mean that, while I was having an experience, there were multiple mental tracks running, where I was seeing and

hearing my performance, where I was thinking about my thinking while the moment was happening, or a “performance sensitive way of knowing” (Conquergood, quote in Spry, 2006, p. 341). I was evaluating and critiquing others, and myself, and I could no longer just ‘be’ in a situation. A sort of critical literacy (of the word and the world) had infiltrated my mind; I knew I was acting and I was teaching my children to act in a certain fashion, and this was what I was trying to capture in this scene. I had actively constructed a persona that I now used in health situations, and I was aware of them, *in situ*.

Despite the fact that I was aware of the multiple understanding and perspectives operating in this transaction, I was also painfully aware of the gaps in my health knowledge. Health literacy advocates putting the onus on the individual to ‘learn’ about his or her ‘condition’ or ‘health’ or ‘preventive measures’, as the case may be. For instance, as a mother, you are supposed to learn about the wonders of immunisations and then you are supposed to bring your child in at the required interval(s) for his or her vaccination. This ‘health literacy’ is not meant to extend to learning about how vaccines are created, either in the past or now; it is not meant to make you question the role the governments and pharmaceutical companies may or may not have in the promotion of vaccines; it is not meant for you to research the molecular biology behind how pathogens create disease in the body or how vaccines interact with or counteract these pathogens.

And this is where I was: I was functionally health literate insofar as I understood enough to schedule, attend, and interact in the vaccination setting; I had a basic understanding of how vaccines work in the body, and I can even use terms like ‘vaccine titres’ in polite conversation. I have a very rough idea of how vaccines are designed and tested in the lab. But I am also painfully aware that there is a whole scientific world that I

have no grasp on, and I was operating in good faith that what I *did* know was enough to make a decision about my child's health, wellness and future. Frankly I would be happier in many respects with a singular identity and blind faith.

On scene xxvi, 2012 November: And So It Begins Again

I extracted this from my initial draft of this scene. It captures well my mindset at the time:

I am still smarting from my encounter at the spine clinic. And not physically.

No: my pain is psychic – my sense of indignation and insult is palpable, even some four days later.

I have spent these past few days trying to

tease out why I am so

enraged, and I think I have arrived at a an

understanding. Distilled to one word,

I am left with

'Expectation'.

Illich argues quite memorably “cultural iatrogenesis...sets in when the medical enterprise saps the will of people to suffer their reality” (Illich, 1976/2002, p. 127). In other words, because the medical enterprise *expects* to be consulted, *expects* to pass judgement, *expects* to be taken seriously, we (‘the people’) likewise *expect* to be cured, or at least ‘managed’. We do *not* expect to suffer without treatment, explanation or, at least, acknowledgement (if not compassion). Suffering is decreasingly part of our cultural lexicon.

Again, from that first draft:

My 'reality' is crippling back pain.

Crippled, as in 'can't move 5 feet, can't sit on a toilet, can't feed my children'.

Sudden, arresting, and consuming,

this pain is thanks to a

'large extruded disc fragment at L3-4 extending towards the right lateral recess and causing impingement of the right L4 nerve root at the lateral recess' (Eesa & Alanazy, 2012, p. 2).

Is this the “suffering of reality” Illich had in mind? Because, I assure you, the suffering was very, very real. Illich does not necessarily distinguish between illness and injury, and for the purpose of a discussion on suffering, neither do I. While I certainly experienced back pain in the past, this was new: it was, of course, different from pancreatic pain, but in many ways it was equally spectacular.

It became apparent rather quickly that the likelihood of a complete recovery from this injury, even with immediate surgery, was slim. Already, within the course of this study, I had arrived at a *second* medicalised ‘biographical disruption’ (Bury, 1982) that put me back into a frame of mind that would require a reformulation of identity (and the development of a concomitant form of health literacy). Again, I was revisiting Frank’s realm:

Serious illness is a loss of the ‘destination and map’ that had previously guided the ill person’s life: ill people have to learn ‘to think differently.’ They learn by

hearing themselves tell their stories, absorbing other's reactions, and experiencing their stories shared. (1995, p. 1)

And again, I was using writing as a way to concretise my new reality, to work through the new meanings, to begin the necessary process of healing, and to effectively learn a new way of life.

But does one "learn 'to think differently'" by constantly repeating their story? Merely recounting the details lacks the *joie de vivre* that true storytelling holds, and that is partly what this study takes up – it is one thing to keep repeating one's story (to the next clinician, the next friend, the next neighbour), and it is another to tell it to oneself, actively using one's own critical lens and one's *currence*.

There are no support groups, no 'remission society' for my particular medical condition(s), nor my longterm physical disability – there is never a return from Parson's 'sick role' (discussed in Illich 1976/2002, Zola 1991, Frank 1995), never that 'becoming whole' that full recovery entails. There is, however, another 'becoming', something along the lines of Foucault's 'becoming' (1982) but it is more like a reconfiguration, or a kind of healing (which is not the same as recovery). One is left with the permanent scars, physical and psychic, but still one has a life to move forward with. One last time I turn to Frank:

The ill person who plays out Parson's sick role accepts having the particularity of his individual suffering reduced to medicine's general rule. Modernity did not question this reduction because its benefits were immediate and its cost was not yet apparent. The colonization of experience was judged worth the cure, or the attempted cure. But illnesses have shifted from the acute to the chronic, and self-awareness has shifted. The post-colonial ill person, living with illness for the long

term, wants her own suffering recognized in its individual particularity; “reclaiming” is the relevant postmodern phrase. (1995, p. 11)

Reclaiming is certainly true, but there is something else there: there is a re-definition of what it means to be ‘me’, and a recognition of what I have learned as a result of this/these experience(s). That, to me, is the kind of health literacy that has a deep value.

Re-Reading the Word in the World

As I have moved through these experiences, I have concluded that, if you only read the pamphlets you are given, if you only read the posters in the waiting rooms, if you only absorb the authorised information you are given, and you make the requisite appointments, take the required shots, undertake the necessary screenings, then you are health literate by professional and policy standards. If you are immersed in your cultural group or subgroup (and most of us are), and you listen to the received knowledge about health and wellness, and you enact that information, then you, too, have achieved a sort of health literacy (although it might not be the dominant Western paradigm, it still qualifies as a form of culturally-constituted health literacy).

Where it all begins to slip sideways, of course, is when a) you don’t do what you are told, or b) what you have learned as part of your cultural experience doesn’t match what is authorised by the dominant health culture, or c) what is authorised keeps changing. You may make a conscious choice, or you might just sort of slide into the realisation. However you arrive there, it is only when you step outside your box, your culturally-defined enclave, and you are open to the world beyond that you begin to see that what you have taken as the Truth about health and wellness is quite possibly not. And the firm ground you once stood upon has disappeared. So you might quite quickly decide to adopt a

new box (switching from, say, a biomedical perspective to a holistic medicine stance), and comfortably inhabit that place for as long as needed. It is only when you realise that there is a space, albeit a scary space, in between these boxes, and that the Truth might not exist in any of these boxes, but perhaps in this scary liminal space – or worse yet, not at all –, that you reach a critical point – the point at which you may never turn back. Because once you *know* that such a place exists, you can't *un-know*. And *that* in when the complicated conversation begins.

I had this exchange not long ago:

Me: *You know, I got a really big shock this week when I was doing some research.*

Friend: *(raised eyebrows) Oh?*

Me: *I was working on the section where I was analysing media sources of health information, so I decided that magazines would give me a glimpse of what's being talked about.*

Friend: *And?*

Me: *And, so I went to Chapters. I looked around and picked up six magazines that I thought would be good representations. I get home, start to do some research, and find that Canadian magazine readership rates are at about 88% of Canadians over twelve years over the past three months; 91% if your household income is over \$100, 000/year²⁰. That's up from 75% in 1980.*

Friend: *Seriously? I would have thought the Internet would have been higher.*

Me: *Nope. But remember, they count e-versions of magazines as straight 'magazines'. Apparently higher education and higher affluence leads to greater*

²⁰<http://www.magazinescanada.ca/uploads/File/Ad%20Services/FactBook/2010/ConsumerFactBook2010EN.pdf>, retrieved Sept 28, 2012. NOTE: This .pdf file is no longer available at this address.

magazine reading and to greater spending. Magazine-readers outstrip television-watchers in their spending, based on the same ads. So, for instance, if you see a magazine ad for a homeopathic preparation, versus a television ad, our demographic is far more likely to remember, and to spend. Basically, we take it much more seriously.

Friend: *Really?*

Me: *Yeah. (pause) I guess what bothers me the most is that I thought I was so independent and so open in my thinking. I thought that the magazines I picked, and the television shows I watched were unique to me. That I was an individual, and that I could see through the marketing, which on an ad-by-ad basis I probably can. But the point is that they have me pegged as a demographic.*

Friend: *What do you mean?*

Me: *I looked up the marketing information for the six magazines, and I found out that the six I considered first (but only two which I bought) are the remains of the ‘Seven Sisters’, a group of magazines that were aimed at us – married women that are homemakers, with children. They’re the magazines I remember from childhood: Ladies Home Journal, Good Housekeeping, Redbook, McCall’s, Woman’s Day, Family Circle, and Better Homes & Gardens. These magazines clearly defined the waiting rooms and grocery check-outs of my childhood memories.*

Friend: *So what does this have to do with demographics?*

Me: *Right. OK. So, I looked up the information, both in the magazine mastheads, and then their corporate marketing departments, and I found out that those specific*

magazines are targeted at me: my social position, my income, my educational level. I'm supposed to notice them. Their design, their positioning, their article titles. And subsequently, I'm supposed to see the ads that are placed within. The various cleaning, health & wellness, family-related, transportation, etc., etc., ads are there specifically because marketers know that I (and people 'like' me) are the most likely to pick up the magazines. It's a game.

Friend: *Are you serious? So we're seeing what they want us to see, right down to which magazines we pick up? They know us that well?*

Me: *I know. Disturbing, right? I dug a bit deeper, and found out the two shows that I watch the most are in the top twelve spots²¹ (and this includes magazines and television) of 'audience'. That's the 12-years-plus age category that they measure for 'number of people exposed'. I have to assume that they're measuring 'average viewership per episode' for television, and 'average readership' per issue. What bothers me most is that I only watch two shows a week.*

Friend: *So are you going to still watch them?*

Me: *Ha! I actually deleted the one right away off my PVR (another reason magazines are far more effective – harder to 'skip' ads – they actually have a word, 'commercial avoidance'!), and the second one I am recording off an American station, so I feel less compelled to get rid of that one. It's funny: the station is out of Atlanta, Georgia, and I can actually feel my 'disconnect' from those ads. Really, I watch them for entertainment. It's all lawyers and claims, sports ads, and job retraining. The demographic difference is stark. But it's also kind of offensive.*

²¹ <http://www.magazinescanada.ca/uploads/File/AdServices/FastFacts/2012ConsumerEN/FastFacts2012Eng7-12.pdf>, p. 6, retrieved September 28, 2012

Friend: *How so?*

Me: *Well, it's so blatant.*

Friend: *I'm sure they'd think the same of ours.*

Me: *No doubt. But that's the point. It's all seemingly positioned as if it's for our own wellbeing – somehow it's going to make our lives better or happier or something. But you stand back...and you start to see something different.*

It is moments like this where I am reminded of Ellsworth's (1997) caution around self-reflection and reflexivity: the terms are not synonymous. Self-reflection does not challenge the self – it simply reflects back the identity as already conceived. It doesn't challenge, change, shift or shatter anything. Reflexivity, on the other hand, does exactly that: through Pinar's process of *currere*, the progressive and the regressive (and the necessarily self-reflexive steps of the analytic and synthetic, are “self-shattering” (pp. 200-201)). This event, for me, was *reflexive*.

This event, this little bit of my research, has bothered me a great deal. It has highlighted for me the inherent difficulty in the notions of becoming ‘critically’ literate (*health* literate, in this instance): for every layer that you unearth in your search for the complicated meanings that imbue all that is around you, there remain layers, paths, and subtleties that you miss. You can excavate forever, and never reach the bottom. So, instead of the question being ‘what is the underbelly?’ it becomes ‘what is under the underbelly?’ etc., etc., ad nauseam.

Now, of course I knew that there was marketing at work in the magazines and other media that I was exposed to: and I fancied myself quite astute when it came to evaluating the symbolism, rhetoric and advertising strategies employed, long before I started this

journey. I *know* it's not altruism that is the prime motivator leading to formula, vitamins, cold medicines, diapers, or soothing lotions being promoted in any given medium. What I hadn't bargained for was the sophisticated use of psychological research that allows such enterprises to get inside my head so very effectively.

But, of course, this sort of mental manipulation has been around a long time. For instance, the social marketing of the 1980s (when I was growing up) was coming into its own as a "technique for influencing social norms and behaviours in populations" (Andreasen, 1995, in Nutbeam, 2000, p. 260), focused on constructing and delivering messages to increasingly well-defined target audiences. Health education campaigns were leveraging the same types of information and techniques, with initiatives such as the Alberta Alcohol and Drug Abuse Commission's [AADAC] Adolescent Prevention Program "Make the most out of a good thing. Make the most out of you." aimed at teenagers (2005), and ParticipACTION's Hal and Joanna and their endless tracksuits and exercise advice aimed at Canadian youth (ParticipACTION, n.d.).

Of course, what the outcomes might be depended upon the content – in other words, what any one learned from the social marketing depended (and still depends) upon what the curriculum of the marketing (read: pedagogy) was/is. Social marketing has been a popular choice for health and wellness messages for a long time (Feather, 1984), with an assumed magnanimity. However, marketing (through media) for health and wellness is most assuredly *not* limited to public health promotion and education messages; capitalist interests convey health and wellness messages about products for sale using these same channels.

Part of this voyage has involved the discovery of my marketing demographic and how it ties into my notions of a health literate self: it is more than a bit disturbing to discover that those things that I thought were unique to me, or at least unrelated to my health worldview, in the strictest sense, were neither. Marketers know which television programs I watch: they know what magazines I am likely to pick up. It is very disheartening to discover that I am so culturally transparent. By placing messages in those places that I am likely to see, hear or read them, social marketers significantly increased the likelihood of my absorbing and ultimately acting upon the messages. When the messages are related to issues of health, wellness, illness, and injury, then they contribute to my culturally-authorized health literacy formation and maintenance, as “pedagogical machines” (Sholle, 1995, p. 145).

In 2011, the Print Measurement Bureau (PMB) found that the *lowest* magazine readership (of a PMB-measured magazine in the previous 90 days) was 75%, in the 65+ age group (recall, this is also the group identified as having the lowest health literacy). It was 89% in the 20-24 year group, and 84% of my group, the 35-44 year olds (Magazines Canada, 2011, slide ‘Magazines are Read by All Age Groups’). So, it was unsurprising, when a short trip to the local bookstore found me faced with a ‘Magazines’ section of epic proportions.

My goal was to pick those titles that I remember being available when I was a child, and that my mother and grandmother read (my grandmother couldn’t read all that well – she mostly clipped recipes). I also wanted Canadian-content publications (with a few international titles for comparison), as well as ‘alternative’ lifestyles, all focused on child and family (i.e. homemaker) orientations. Why? Well, really I had three reasons: the first

was continuity (titles in continuous publication, and therefore successful to some degree), the second was nostalgia, and the third was a focused evaluation of what was/is being said to my generation of mothers/homemakers. Especially in the case of the ‘alternative lifestyle’ magazine(s), I was aware that these ideas wouldn’t have been readily available to my mother or grandmothers, in part because these lifestyles were simply not mainstream enough to support a magazine’s publication. However, they are most certainly available today, aimed at my current “white, affluent, educated” demographic.

I ended up purchasing *Ladies’ Home Journal* (October 2012), *Good Housekeeping* (September 2012), *Canadian Family* (September 2012), *Today’s Parent* (September 2012), and *EcoParent* (Fall 2012). Every single one had (at least) a web version, and in some cases, an iPad version as well (*Today’s Parent*).

Then I went home to do some background research, not entirely sure what I’d find. I learned interesting things like *Ladies Home Journal* was first published in 1883 in its own right, though it began as a supplement. It was the first women’s magazine to attain a circulation of one million copies, making it a household name. Its Wikipedia write up states “During World War II, it was a particularly favored venue of the government for messages intended for housewives” (Wikipedia, n.d.). I, like many, question the veracity of some of Wikipedia’s content, so I ventured to the *Ladies Home Journal* website, where it claimed

For the past 125 years *Ladies’ Home Journal* has served as a chronicler of American life in its glories and challenges, through world wars and cultural earthquakes, all through the lens of a woman’s ever-shifting experience and perspective. (www.lhj.com)

This, of course, sounded pretty good: sort of like it is responding to, rather than defining, women's needs and experiences, analogous to a trusted friend. This would be misleading, though: ultimately a magazine's viability is dependent upon the intricate balance between advertisers' dollars and readers' perceptions, mediated by the magazine's content.

Good Housekeeping was established in 1885, viewing itself as having a "mission to fulfill [sic] compounded of about equal portions of public duty and private enterprise...to produce and perpetuate perfection as may be obtained in the household" (Clark W. Brian, May 2, 1885, as cited in *Good Housekeeping*, <http://www.goodhousekeeping.com/product-reviews/history/good-housekeeping-seal-history>, para. 1). In addition to being an early advocate of pure food (meaning unadulterated), even before the 1906 Pure Food and Drug Act, the publication was anti-tobacco, and promoted the Ludlow Amendment (which required a direct vote from the citizenry in support of the declaration of war). Politically, it was far more liberal, and viewed itself as carrying the torch of public knowledge and health, as it was experienced and enacted in the homes of its readers. Today, its mandate reads:

Good Housekeeping magazine—together with the Good Housekeeping Research Institute and the Good Housekeeping Seal—is an American icon of consumer protection and quality assurance. Every issue delivers a unique mix of independent investigation and trusted reporting, along with inspirational and personal stories. The magazine's rich editorial tradition embodies a commitment to the modern home and to a woman's quality of life. (Hearst Corporation, 2009)

It is certainly possible to read the curricular intent as subtext in this passage: after all, by providing 'approved' products and various other pieces intended to improve 'women's

quality of life’, the supposition is that readers will *read* and then *enact* such improvements – and where those items are related to health and wellness, these actions constitute a magazine-authorised ‘health literacy’. The question of whether such bits of advice reflect, or shape, women’s perceptions and perspectives remains to be seen.

Unlike the previous two titles, *Canadian Family* is a Canadian publication (the first two are American, despite enjoying enormous Canadian readership), and positions itself as a magazine that

embraces a new approach to parenting; one that respects both moms’ and dads’ needs as well as the kids....*Canadian Family* is an invaluable guide for a new kind of parents who are up on the latest trends and products, but craves style, decor, food and parenting solutions for their busy life. (St. Joseph Media, 2013, right sidebar)

This is what they would like you to know about their magazine, and about who you will “be” when you read their magazine. In September 2012, this is what they told their would-be advertisers:

Your brand, seen by the right buyers.

Our properties speak to readers on local and national levels, offering you access to the broadest range of people and interests. Compared to our competitors, St. Joseph Media delivers the best-targeted media brands for reaching affluent, educated and urban adults aged 25-54. And we create active social networking communities that inspire the comments, ideas and loyalties of our readers. That means you’re in touch with consumers during the prime spending years – people with a desire to spend money and money to spend.³⁷

³⁷ Note: This webpage is no longer available. It is replaced with the page described in the following paragraph.

In the intervening year, they have pushed further with their strategies, developing and advocating something they are calling ‘omnichannel’. In their words:

We define omnichannel as differing from multichannel in that “its goal is not solely to optimize the broadcast of content across customer touch points, but rather to create a media-agnostic infrastructure that links products, consumers, and communications channels together. This creates an ecosystem that is constantly evolving and getting smarter as new data is received. (Naldinho, 2013)

If you’re wondering what a ‘media-agnostic’ is (I certainly was), www.cheesycorporatelingo.com defines it as “media neutral. It’s supposed to mean that there is no preference for a given media channel in advertising, but it really just means the agency doesn’t know what it’s doing and doesn’t want to commit to anything lest it appear stupid”. Referring back to St. Joseph’s definition of ‘omnichannel’, and approaching the idea a little less cynically, I am aware that what they’re really getting at is that they intend to get to their consumer any way that they can.

Today’s Parent, published by Rogers Media Inc., with a circulation of about 160 000, and a monthly Canadian readership of 1.7 million people, says this about itself:

Who We Are? *Today’s Parent* is Canada’s #1 source for parenting content that informs, inspires and builds a sense of community. We help parents celebrate the happy chaos that comes with having a family and remind them that they are not alone. If you have children from birth to ages 9+, you’ll get insightful information for all ages and stages on discipline, health, behaviour, education, plus easy and nutritious recipes and so much more.

Our Mandate. *Today's Parent* has been the most trusted source of parenting information since 1984. We speak to parents in a fun, friendly voice with a positive attitude. We don't preach, and we don't pretend to have all the answers, but, through real-life stories and expert advice, we empower parents to make informed decisions that are right for their family, and provide them with a good laugh from time to time. Our goal is to inform and inspire our audiences, and create a sense of community. (<http://www.todaysparent.com/about-us/>, retrieved November 14, 2013)

At Rogers Publishing site, where you will find the 'new' information about *Today's Parent*, it claims that:

It's a parent's best friend. *Today's Parent* magazine is Canada's favourite source of parenting information for parents of children from birth to age 14. Together with our popular website [Todaysparent.com](http://www.todaysparent.com), we deliver information, ideas, activities and a community of engaged parents that's unparalleled in Canada. *Today's Parent* connects Canadian moms who are raising kids in the real world. (<http://www.rogersconnect.com/publication/today-s-parent>, retrieved November 5, 2013)

Of course, there is no way to tell just how long *this* particular vision for the magazine will remain posted. However, I do find the explicitness of the final sentence intriguing: after going to great lengths throughout the blurb to use the inclusive language of 'parents', they finish off by saying '...connects Canadian moms who are raising kids in the real world'. Did you catch that? *Moms*. All rhetoric aside, they know full well who the vast majority

of their readership is, make no mistake. And as such, the assumption can be fairly made about *who* the articles and advertising are geared towards.

The niche magazine market has increased its market share (Magazines Canada, 2009), and *EcoParent* (“making better choices happen”) is representative of this phenomenon. Their mission statement states they are:

...giv[ing] you what you need to make responsible, sustainable and, most importantly, attainable lifestyle choices for your family.

- Informative and non-judgmental in approach
- Fun and inspirational in tone
- Promoting engaged parenting and lifestyle choice
- Relevant and do-able for the contemporary Canadian family

(<http://www.ecoparent.ca/page/our-mission>, retrieved November 2013)

Again, the rhetoric of collegiality and empowerment pervades the level of communication that is readily available (‘transparent’) to the average reader (most of whom, let’s be frank, don’t bother to read the mission statements on much of anything). In November 2012, the media kit, in addition to outlining distribution, identified its target market as “Canadian women between the ages of 25 and 45, evidenced by the fact that 75% of our more than 1,700 current Facebook ‘likes’ are coming from this demographic. But dads seem to like us too. They are all passionate about making better, more responsible choices for their families”³⁸. The 2014 media kits states that, based on their Facebook ‘likes’, their readership consists of “25-44 year old females: 77% Canadian: 71% North American: 94%) (http://www.ecoparent.ca/mediakit.pdf, 2013, p. 5). Evidently, they are

³⁸ <http://ecoparent.ca/MediaKit2012.pdf>, retrieved September 26, 2012. NOTE: This page is no longer available. It is replaced with the 2014 information cited above.

extrapolating this information from a) the personal information people on Facebook (regarding age and interests, perhaps including Wall Posts) and/or b) the pictures people post. It's not clear how they go about delineating the age and passions of the Facebook 'likes' (and notice they've doubled in a year?), but their statistics seem to indicate that I would be in their marketing demographic. Published since May 2012, it prides itself, as its cover says, on being a "Genuine Canadian Magazine", it also appears to be published independently, rather than as one of many in the stable, which in turns makes it more flexible (perhaps) and more vulnerable (for certain).

When you read all of this market positioning and masthead information do you feel patronised? How about like you've been spin-doctored? Did you laugh contemptuously? If you had more information of this sort, straight from the purveyors themselves, before you opened a magazine, visited a website, or watched a television program, how much more critically would you react? I think most of us *know*, when it comes down to it, that advertising is not an essentially benevolent trade; we *know* that it is driven by the capitalist enterprise. Yet we spend a woefully small amount of time actually considering what is put in front of us and it's effect upon our mindset(s) and our actions. Unevaluated and not reflected upon, such messaging will assuredly form a sort of 'literacy', but it cannot ever be called 'critical'.

So, with all of this new information in hand (limited though it might be), I sat down with my magazines. I wanted to encounter them with the critical eye that I had been developing through the unique interaction of education and experience that I was mapping as *currere*, and exploring as instances of health literacy. What would I see now, that I likely would not have seen even a few years prior?

Well, some basic statistics might be interesting: *Ladies Home Journal* (2012) (134 pp) had 36 pages of health- and wellness-specific advertising. Pharmaceuticals were well represented: Lunesta, Livalo, Cymbalta, Restasis, Advair, Vesicare, and Zostravax had 1-3 page spreads. Other ads included sanitising items, diet products, skin care (I did not include cosmetic skin care in my counts), and supplements. *Good Housekeeping* (2012) (216 pp) had 50 pages dedicated to similar products, with pharmaceuticals such as Pradaxa, Advair, Spiriva, Pristiq, Symbicort, and Livalo, and a huge number of pet-health related ads (which are not included in the magazine total I provided). *Today's Parent* (2012) (163 pp) featured 34 pages of marketing geared towards health and wellness, with multiple dental hygiene (5 – Crest Pro-Health, Crest Pro-Health ‘For Me’ 8+ years, Crest Complete + Deep Clean, Crest Complete with Scope Dual Blast, and Scope Dual Blast (‘the onionator’)) and infant formula (3– Similac Advance once, Enfamil twice) pages, and no pharmaceuticals that were not OTC (over the counter). The presence of the formula ads were interesting, especially since the last page of the magazine, ‘The Debate’, was “Would you breastfeed a child past age two?”

EcoParent (2012) (at 78 pp, the smallest in the sample) was printed on noticeably different paper, more like a coloured newsprint, not glossy. As only the second publication in the magazine’s history, there was a notable absence of marketing. Mostly ¼ and ⅛ page ads pepper the copy, but the majority of the magazine was dedicated to either articles or product profiles. Nearly every page of this magazine might be argued to be health and wellness orientated, by simple virtue of the fact that the ‘eco’ movement advocates awareness of behavioural decisions that impact our health and the health of the planet/ecosystem, such as what we eat, what we wear, what we teach our kids, and so forth,

in a much more transparent fashion. It is all couched in the moral and ethical imperatives of the 'green' movement. However, it is very possible to turn the crystal a bit and see something different: as in, perhaps the messaging in this magazine seems more foreign to me simply because it is not what I am accustomed to (though, to be honest, I am accustomed to a lot more of it than my mother or sister ever will be, because I 'run with that crowd' a bit). By the same token, it is entirely possible to read the 'mainstream' magazines as advertising a certain worldview on every page as well, not just in those explicitly marked as advertisements. It is a worthwhile observation to bear in mind.

Finally, *Canadian Family* (2012). Ninety-two pages in length, it sports 20 pages of health-related ads (and one Public Health Education page from the Heart & Stroke Foundation). An additional ten pages feature non-health ads, and there are four articles about child health within the magazine. This magazine obviously caters to families with younger children, if we are judge by the types of ads represented: teething (2), skin/sunscreen (2), diapers (4), supplements (4), tissues (3), food (2), formula (1), breastfeeding (1) and dental health (1).

It's when I visit the *Canadian Family* webpage that something especially catches my eye (though undoubtedly it will be long-gone by the time this is in print) (Figure 1): I learn that, if you provide your personal information (and this is how they collect such precise demographic information for marketing purposes), you will be entered to win "Wonder Bumpers" or "Norbert the Nightmare Nibbler". The names alone give much cause for amusement. Apparently, Norbert is "the first member of the Nightmare Nibbler Nation" (N³) to arrive on Earth" (Nightmare Nibbler, n.d.), a plush toy meant to alleviate children's fear of the dark and 'monsters under the bed'. While the toy's development was

based on a mother's exigency, somewhere along the way someone obviously said, "You really need to market this!" What is a common childhood occurrence (nightmares), traditionally treated with comfort and soothing, has become an opportunity to make a treatment 'product' (in China) and sell it in Canada and the US. But you're not supposed to think of this.

Figure 1 Sleeping better with Wonder Bumpers ad, September 2012

The advertisement is a rectangular graphic with a white background. At the top left is the Trillium Sales & Distribution Inc. logo. In the top center, the word "WIN!" is written in large, bold, black letters, with "a complete Wonder Bumper Nursery Set" in purple text below it. At the top right is a circular logo for "Go Mama Go Designs". Below the text is a photograph of a nursery room with a crib, a dresser, and a window. Below the photo, the text reads: "Trillium Sales wants you and your child to sleep better minus 'any' worries - whether they be real fears OR imaginary fears!". To the right of this text is a plush toy of a brown and white creature with large ears, next to a book titled "Norbert the Nightmare Nibbler". Below the text and image is a purple button with the text "ENTER BELOW TO WIN!". At the bottom right is a logo for "Nightmare Nibbler" featuring a small yellow creature.

Contest ends: 2012 October 24

Lay your worries about your baby sleeping to rest with Wonder Bumpers (by Go Mama Go Designs) - the safest bumper alternative on the market AND put your child's nightmares to rest with Norbert the Nightmare Nibbler (by the Nightmare Nibbler). Prizes will be awarded to 2 lucky winners! 1st prize is a complete Wonder Bumper nursery set (choice of boy, girl or neutral), which includes 38 reversible bumpers, crib sheet, toddler blanket, crib skirt. 2nd prize winner takes home the lovable Norbert the Nightmare Nibbler and his story!⁴⁰

⁴⁰ <http://www.canadianfamily.ca/contestpage/?slug=sleeping-better-with-wonder-bumpers-nightmare-nibbler-products1>, retrieved September 28, 2012. NOTE: Webpage no longer available

This provides an 's of how a communications corporation (St. Joseph), through a print and digital magazine aimed at parents (*Canadian Family*), partners with a company (Nightmare Nibbler) to sell a product to families based on a perceived need around sleep hygiene and mental health. Part of me wonders how many parents saw this ad, and then decided that this was something they needed (or at least should have) in order to be a good parent.

What has this got to do with the idea of health literacy as an emerging (and evolving) concept? After all, any number of 'health and wellness' products has been discussed, advertised, hawked, and so on, in the media since its advent (McLuhan, 1964/2003). It's not that it's a new phenomenon – rather, I am attempting to illustrate what can occur when the affected individual (one coming into contact with the health and wellness marketing) stops and 'unpacks' the experience, lays the process out for others (and her- or himself) to reflect upon.

When I first pulled this ad for analysis, my first thought (beyond what I've already outlined) was around Sudden Infant Death Syndrome (SIDS). *Wonder Bumpers* (<http://www.gomamagodesigns.com/faqs/wonder-bumpers>) are vertical bumper pads. Most middle class Western mothers are familiar with the potential for an infant to suddenly die in their sleep (as are other cultures' mothers), and the debate about bumper pads' contribution to SIDS rages on (if you want to be overwhelmed, just Google 'SIDS'). In no way am I minimising this: this tragedy has touched my family.

The facts, though, are relative, and in some ways in short supply. For instance, in Alberta, in the period 1985-1989, there were 291 postneonatal SIDS deaths, a seemingly large number, second only to British Columbia's 318 (Rusen, Shiliang, Joseph, & Kramer, 2004). Closer inspection, however, shows that when this is viewed as 'per 1000', Alberta's number moves to 1.36/1000, third to the NWT's 2.16 (16 SIDS deaths in the period). In the period 1994-

1998, after the ‘Back to Sleep’ program was launched, those numbers shifted in a substantial way. According to Rusen et al.’s report (2004), Alberta moved into fourth place at 0.80/1000 (or 153 postneonatal SIDS deaths). Between the move in sleeping position, the boycotting of bumper pads, the decrease in maternal tobacco use and infant exposure to second-hand smoke, and awareness around room temperature and infant clothing choices, somehow the numbers decreased. The fact is we do not know precisely the mechanism that causes SIDS, nor the real causal connections between these various sleep hygiene considerations and SIDS’ occurrence (Public Health Agency of Canada, 2011).

However, Wonder Bumpers would like us to treat the ‘innovation’ of vertical bumpers (a bumper per slat) as progressive and for our children’s health and wellbeing – a way to allow for the comfort and cuteness of bumper pads, while mitigating SIDS risks –, and not a commercial enterprise aimed at middle-class and affluent buyers. With horizontal bumper pads now banned in Maryland, and illegal for sale in Chicago, Illinois (though not in the rest of the state), the Juvenile Products Manufacturers’ Association (JPMA) has had to work to ensure that the product’s market share remains intact, and vertical bumper pads respond to this ‘need’. Their argument for bumper pads’ efficacy lies in the fact they prevent bumps and bruises, and they prevent limbs from being caught (less and less the case as crib slats are being built closer and closer together). The JPMA advises: “Use bumper pads only until the child can pull up to a standing position. Then remove them so baby cannot use the pads to climb out of the crib.” (Juvenile Products Manufacturers' Association [JPMA], 2010).

On the other hand, Kids in Danger [KID], a consumer advocacy group, holds that “There is no research that shows a baby can push up against the bare crib rails with enough force to cause severe injury,” and further, that “we know babies have suffocated on crib bumpers and

they are an unnecessary and dangerous product” (Kids in Danger [KID], n.d.). They say nothing whatsoever about differences between ‘traditional’ horizontal and ‘new’ vertical designs. As a parent, what do you do? As a magazine advertising department, what do you do? As a designer and seller of bumper pads, what do you do?

Okay, as a mother, you decide to NOT use the bumper pads grandma made, just a flat, unadorned mattress in the crib. Oh, but the mattress...hmmm, the mattress itself might be a problem. Visiting the public forum at www.mothering.com, a thread (started on November 13, 2004, at 2:40 am) entitled “Ending the SIDS fears?” has a response from member ‘mommybritt’ that says

...90% of all deaths from SIDS occur between the ages of 1-6 months and the majority of those happen from 2-4 months.

Another thing to consider is that there is a researcher in NZ who believes that SIDS is not a mysterious syndrome that randomly kills infants but that it does have a cause (toxins released from crib mattresses) and that it can be prevented. I wish I remembered his name but a search might do it. His research is very plausible and supported by many, it just hasn't really reached here yet...

She is referring to chemist and forensic scientist, T.J. Sprott, author of *The Cot Death Cover-Up?* (1997), whose work is actually preceded by a British scientist and materials consultant, Barry Richardson (1994). Sprott maintains a website, <http://www.cotlife2000.com/>, that outlines his theory, refutes misinformation on the Internet, and sells his *BabySafe* mattress covers. Needless to say, Googling this topic, mattress toxins and SIDS, opens a veritable Pandora’s Box: today (November 13, 2013), in .25 seconds, Google pulled 47, 800 hits. I won’t be reviewing them all today.

I've established both the bumper pads (now removed) and the mattress (now covered) could have caused my child harm. I now discover that the *crib itself* could be dangerous. Health Canada, between 2010 and 2011, has issued numerous product recalls for drop-rail cribs (Government of Canada, n.d.). In June 2011, the United States banned all sales of drop-rail cribs. Kids in Danger (KID) dedicates a page to the topic (<http://www.kidsindanger.org/product-hazards/cribs/>), along with sidebar scrolling stories of related fatalities. Testimonies range from strangulation to crushing. It's a deeply unsettling page for any parent to view, I'm certain.

So, now I've removed bumper pads, covered the mattress, and bought a new crib (or installed industrial-strength immobilisation hardware). I've definitely *not* signed up to win WonderBumpers or Norbert. My child is safe. Problem with all of this? Indeed. My children, born in 2005 and 2008, respectively, had bumper pads, uncovered mattresses, and drop-rail cribs. They both survived infancy (thank god), and perhaps it's blind luck. But if I take this line of reasoning to its logical conclusion, that progress will always find new ways to improve on old hazards (even if we don't currently know they are hazards), then, as a mother, I have always been, and will always be, operating in a health and wellness minefield I can't even see.

While contemplating my new nephew the other day, my mother-in-law, who was officially babysitting, started talking to me about how the baby needed thirty minutes every day on his stomach.

"Oh," I said, "Tummy time."

"Yes, well, I don't know why people don't just put their kids on their backs like they used to."

"SIDS."

"I know that: but it doesn't make any difference."

*“Well, yes, there’s a statistically significant
difference between the incidence of SIDS
when children are tummy-down versus on their backs.”*

“Well, we put kids on their tummies—“

“—so they didn’t choke. I know. It’s a trade-off.”

“I think it’s ridiculous. How do they know it’s better?”

*They say the same thing about bumper pads and
all my kids had them.”*

“As did mine. It was that or cork themselves when they rolled over.

*But it wasn’t ‘advised’. They think it has
something to do with airflow across the crib.”*

“They don’t know what causes SIDS.”

“No, I don’t think they really do.

*They have a lot of theories, and
data that shows that when this is done,
this is more likely to happen, and when that is done,
that is more likely to happen.*

It’s not like they can run an experiment on this.”

*“No. But I don’t see how they can say that
lying on backs is better than tummies.”*

*“Do you really want that answer?
Because I can dig out the research.”*

“No.”

“All right. Like I said: it’s a trade-off.”

*“I’ve never seen a baby that died of SIDS
because of bumper pads.”*

*“Well, a child I babysat died because of bumper pads
and a slightly humped mattress.*

*He was a weak and sickly child,
got himself somehow over to the bumper pads,
and was too weak to cry out or roll over.*

*And my cousin died of SIDS in the hospital when he was three days old
(even though I’m not sure if it ‘qualifies’,
because he was young than 30 days,
and they used to call it ‘Crib Death’). So……”*

“Yeah.”

“It’s a trade-off.”

The process I’ve taken you through hints at the complexity of what any one person is faced with when attempting to move beyond the ‘taken for granted’ or surface appearances. This illustration is but one topic: motherhood, patienthood, lifehood is rife with such moments. I have spent a few hours working through this one example (and I have intentionally cut myself off, even though I know there is much more to explore and consider); I have used my Internet connection to research these questions (and I purposefully stayed clear, at least in this section, from anything that is only accessible with an academic library account, like I have as part of my PhD program). These points beg the questions: without time and/or without an Internet connection, would I be a) a more or less health literate mother, and b) more or less confused?

I am certainly using my educational experiences to leverage my learning about health and wellness matters (in this case, through magazines, and then through the Internet); I can make sense of statistics, find competing arguments, engage in a critical analysis of the materials available to me. I am, to every available measure, 'health literate': yet, my country says bumper pads are still legal and our neighbouring country has outlawed them. Where does the concept of 'health literacy' fall in this case?

Act Five: The Progressive

Stories, like bodies and in symbiosis with bodies, are people's dignity and their calamity

(Frank, 2010, p. 146)

Biography has recently become especially interesting for two reasons. One is that some scholars have turned away from grand historical narratives, and biography offers them a way of retaining narrative without taking responsibility for explicit generalizing beyond a general life. The second reason is that, as in medical education, cases do teach.

(Burnham, 2005, p. 29)

As we bungle along, understanding and misunderstanding, we require above all a recognition that we have only each other to work with. Making sense of that in a positivist, secular culture seems to me to be the major task confronting medicine today. We are better guided by the humility of uncertainty than the shame of ignorance.

(Baron, 1990, p. 28)

Imagining a Future, Family Resemblances, and Further Conclusions

Coming to the final Act, I look back, and see two major outcomes of the work. First, I recognise that the process I implemented through *currere* has led to a much deeper, reflective understanding of the major identity disruptions that I have undergone over these eight years. In many ways, this study has contributed to a form of healing that I had not anticipated at the outset. Second, by more closely examining the Western biomedical experience of a patient and a mother, I have identified a much wider variety of understandings (and applications) of the nascent notion of health literacy than is captured in the extant literature. By placing the auto in the ethnographic I have been able to tease out health literacy's implications in ways that perhaps asks more questions than it answers, but nonetheless provides a promising start for future examinations.

Early on in this work, I refer to the to various elements (education, motherhood, patienthood) as having an “impact” upon my thinking. If I visit my thesaurus, I find the following provocative alternatives for ‘impact’: crash, collision, and shock (Merriam-Webster, Inc., 2013). It is these three that most interest me, as they are truly the most apt. They elide well with the title I had always intended to use: ‘Critical’. These ideas and experiences have had that sort of catastrophic effect on me, so much so that I will not – not ever – recover. But I might heal.

When I read back, I note with chagrin my words “I didn’t undergo any of the transformative experiences that so many write about – my change was spurred on by something far more subtle and creeping. Education changed me” (pp. 5-6). That’s a lie. No, not that ‘education changed me’ – that part is true—, but the ‘transformative experience’ bit. The simple

fact is, had I *not* been interrupted by critical illness, *compounded by new motherhood and new directions in education*, then I would have committed the existential crime of complacency Frank warns of:

Critical illness offers the experience of being taken to the threshold of life, from which you can see where your life could end. From that vantage point you are both forced and allowed to think in new ways about the value of your life. Alive but detached from everyday living, you can finally stop to consider why you live as you have and what future you would like, if any future is possible. Illness takes away parts of your life, but in doing so it gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years. (1991, p. 1)

What I failed to see for a long time was that I had been taken to the edge: I have simply used, due to chance or circumstance, writing as a way to find my way onward, past the borders of what I knew or ever felt I could know. It is, in effect, my quest. The challenge that I didn't readily recognise was that there would never really be an end – there is no holy grail, and the horizon will always be out in front of me, just beyond my grasp. But now I see that there is an ever-moving horizon, even if I can't ever see its edge.

The process of coming to understand 'health literacy' through my own personal experiences' lens has been both frightening and enlightening. Frightening, because once one starts to appreciate the complexities, and the fragility, of those things that undergird notions of health, one cannot black it out; enlightening, because the awareness that such critical reflection affords allows a deeper understanding and engagement with those everyday choices (and those that can never be 'choices') that answer the question "how do we learn to take care of bodies?"

Denzin (1986), in discussing Lyotard (1984) perfectly captured what this auto/ethnographic exploration of health literacy and personal experience results in in his words:

Modernism...presents the real and the sublime in an aesthetic that is acceptable, and produces solace and pleasure. The “real” sublime, however, produces pain and discomfort and this is the underlying goal of postmodernism: to produce, that is, a massive and painful reflection on the present...The postmodern task becomes one that...pays the price for the terror that is produced by dis-order; feeling that for too long we have paid for nostalgia and a desire to reconcile the real with the conceivable. Postmodernism thus urges a war on totalities, while it bears witness to the unrepresentable and activates the differences that exist in the social, cultural and historical realms of the everyday. (p. 202)

By taking up health literacy through the strategies I’ve outlined, I’ve attempted to “bear witness”, and in doing so, I’ve striven to “activate the differences” in the various conceptions of health literacy operating in the Western biomedical realm at this juncture.

In order to begin to understand how the various incarnations of health literacy, as experienced and depicted in Act III, operate in the ‘real world’, and to use those understandings to formulate a deeper, more complicated appreciation of ‘health literacy’, it is important to contemplate *why* such ‘definitions’ of health literacy have been created. Rorty has the most sensible response, I think: “The right question to ask is, ‘For what purposes would it be useful to hold that belief?’” (1999, p. xxiv). Those are the answers that have the most insight.

Health is something that affects every single person on this planet, regardless of income, education, gender, class, location, religion, time period, or philosophical persuasion. We have bodies, and those bodies come with realities. How we interpret those realities, and how we

attend to those realities, vastly differs, but each person who makes choices (or has ‘choices’ visited upon their person (Macedo, 2006, p. 165)) is affected by deeply entrenched, complex notions of health – and it is those influences that are necessarily the foundations of any understanding of health literacy. Health and wellbeing are just as important to a middle class mother in North America as they are to an unemployed man in Peru. Women in Sub-Saharan Africa and children in Siberia are both products of and (increasingly, typically, over a lifespan) producers of health for themselves, their families, and their communities, and in producing health, they are activating certain conceptions that we can understand as ‘health literacy’.

It is in the *how* that we differ. How we understand ‘health’, and how we act upon those understandings, are the key differences. ‘Health literacy’ is frequently understood and positioned as a developmental path for those that have *less* – less education, less income, less status, less political clout, less support. The measurements and interventions that are designed to give those with less *more* (more health = more longevity = more productivity = more happiness), miss a fundamental aspect of health literacy, one that until now seems to have been obscured: health literacy is *not* matter of bringing everyone around the world up to speed on a global notion of health (which, we must acknowledge, wears an increasingly technology-driven, mechanistic, medicalised Western face). Health literacy is about the *process* by which we come to an understanding, personally and politically, of how health is constituted, how decisions are made, how limited resources are allocated. And health literacy is also about how we come to terms with our limitations: physical, spiritual, informational, technological, philosophical, intellectual, cultural and emotional. All of the discursive acrobatics around ‘health literacy’ – all of the varying definitions, measurements, interventions, communication strategies, and training courses

– are but another attempt at an answer – insofar as it prescribes a worldview (and often a content-base) for responding to our physicality.

The fundamental question underpinning any notion of health literacy is really quite a simple one: how do we learn to take care of our bodies? The answer, however, is anything but simple. “How” “We” “Learn” “Take Care” “Our” “Bodies”: each of these encompasses a world of ideas, histories, responses, and conflicts. Of course these differ from time to time, place to place, culture to culture, community to community – that much is to be expected. Those are the instances of health literacy that are often written about in the scholarly literature and addressed in policy documents, and while complicated, they are still negotiable.

Kleinman (1988) pointed out that “[our illness narratives] tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation” (p. xiii). But when an *individual’s* experience of the answer to these questions and situations is not consistent, both intrinsically and extrinsically, the ability that this person has to answer this question for his- or herself is likely to devolve. For instance, when this understanding is complicated by identity disruptions such as illness, injury or motherhood, the complexity increases exponentially in such a manner that what constitutes “health literacy” in the patient identity may be in direct conflict with what passes as “health literacy” as a mother.

Attempting to define ‘health literacy’ and, from there, design curricular interventions that ‘remedy’ the gap that exists between ‘literate’ and ‘illiterate’ realities (or at least the perceptions of) does little to honour the individual’s or the community’s ability to create his/her/their own understandings, approaches and solutions, and in doing so, further homogenises a world that desperately needs diversity. It isn’t that it makes sense to cut communities loose and let them

decide how to apply scientific medicine to their situations. However, is there room for notions of health literacy that allow individuals/communities information without prescriptions? Basu & Dutta (2008), working within the field of health communication, and outlining an emancipatory-participatory framework for community health, captured the nuance perfectly:

A health communication model within a participatory community-based framework empowers members of the community to articulate their needs, map available resources, mobilize them in the production of positive health outcomes, and engage in sustenance behaviours. This ability of a community to be accountable, participate, develop, and maintain preventive behaviour is played out in terms of social capital. (p. 70)

It is there, in such simple words: articulate, map, mobilize, engage...accountable, participate, develop, maintain. These words point us in a direction that is not delineated by the word compliance, but is perhaps more generously corralled by the idea of 'responsibility'. Each, of course, implies duty, but the nature of the obligation is more open to interpretation.

As I explained early in this study, the goal was to unpack health literacy through the particular experiences of one individual, because

We do not know how this new information age is lived on a daily basis by ordinary people. We do not know how the meaning structures which are arising in the postmodern age find verification in ordinary lives. Schutz's man on the street has been transformed into an expert on the happenings with the global village that constitutes the world system. How this information then enters and circulates within the realm of the taken-for granted is not understood. (Denzin, 1986, p. 202)

Before taking exception to my picture of 'health literacy in the 21st century', and the seeming critique that have presented of the scientific/biomedical process and system, I offer that I am *not*

opposed to medicine or medical intervention, nor do I think that individuals shouldn't have responsibility. Further, it is difficult to argue against the more equitable distribution of all of the things that constitute quality of life, such as power, resources, education, opportunity, or healthcare. I *do* believe that individuals should have support and choice, and the freedom to exercise those choices (within, of course, those caveats of culture and society), and I *do* believe that education and communication *are* key components of making this vision possible.

But what I *do* take exception with is the seemingly limited notion of the nature of the challenges that face people – all people – in the pursuit of this thing we call ‘health literacy’. By setting ourselves the task of defining, measuring, and intervening upon this notion, we necessarily take focus away from something equally important: understanding how these notions impact people. Not theoretical populations, not test cases in constrained clinical ‘empirical’ settings, but real people navigating through these realities every single day. This is the information that is perhaps most telling, and the most untold (Church, 1995; Dent, 2007).

How might we get at such accounts? This is a question that I have frequently asked myself over the course of this study. A few doctor-authors have written both about their experiences (Groopman, 2005; 2007; Kleinman, 1988) and about the role of narrative in medicine (Charon & Montello, 2002; Charon, 2006; Rapport & Wainwright, 2006; Kleinman, 1988), and I have no doubt that these accounts are useful for practitioners contextualising their professional and personal lives. Scanning the environment for extant critical narratives on health literacy told from the ‘bottom-up’ and exhibiting literary quality, yields little (though, admittedly, the Internet has given many people a newfound platform to chronicle their illness journeys, and that was expressly not the case when this study began). A few notable exceptions that might arguably be taking up health literacy (though not named), such as Oliver Sacks

(1984), Anatole Broyard (1992), and Arthur Frank (1991), exist. Female versions— especially mothering females (Wolf, 2001), who have a great deal of impact on how and what future generations learn about health – have been largely absent.

Why that is, I think, is largely a matter of the voices mothers are permitted to use: to speak about the experience of mothering is, at the very least, un-academic, and at the very most, emotional: neither of which is valued in the larger discourse community dedicated to matters of health and medicine (Zola, 1991). And even that statement presupposes a social position where such a voice would even be *allowed*. Virginia Woolf also pointed out (and correctly, I believe) that women are too busy being wives and mothers, and *females* generally, to have a voice of their own – a room of their own (Wolff, 1929/2011). I am not entirely certain that those days are behind us, even in this post-modern, Western world.

In contributing my narrative(s) and analysis to the discussion, I am stepping outside what is considered the ‘norm’. In reflecting upon what I have said in these pages, the *currere* that I’ve outlined, I am fully aware that I am, in many ways, an outlier. I am, by most available measures, privileged: therefore, I am already speaking from a position of dominance. Presenting my reflexive encounters with notions of health literacy is an attempt to make transparent the process that I have gone through, not a usurpation of the notion for yet another middle-class diatribe that fails to acknowledge the hegemony of class. I do not speak for anyone other than myself, but I hope that others recognise their own truths in my words, no matter their personal history. Perhaps I can accomplish Frank’s (2000) imaginings:

While autobiographical work is necessarily “framed” within the horizon of systems of honor credited in a given time and place, certain individuals exhibit sufficient agency to push those horizons toward inclusion of new claims. Their sense of themselves as ill

people [or injured persons, or mothers dealing with children's health and wellness] is not the normal, social identity-by-default. Rather they put together performances that claim different selves and thus make available to others the systems of honor in which those selves are creditable. (p. 4)

In other words, by conveying my own quest in terms that are accessible to others (despite the risk), maybe others will extend themselves similarly. Opening up a larger dialogue on the meanings and implications of health literacy could be valuable across many sectors and populations.

'Health literacy' risks becoming a homogenising force, for the simple reason that, by authorising certain understandings and actions as *health literate*, and others as not, it operates as a hegemonic discourse. The implicit message in much of the messaging around health (and hence, "health literacy") is that there is a *right* way to behave, and a *wrong* way to behave, with respect to caring for one's body and the bodies of others. While it is certainly true that improper use of antibiotics breeds 'superbugs', and that faecal contamination spreads disease, it is perhaps *less* straightforwardly 'true' that everyone ought to live to 100 (and that we should all behave as if that is our goal). Part of the challenge is in identifying where scientific medicine is useful and effective, and where it is less likely to be so – and maintaining boundaries that guard against the sort of encroachment that strips individuals and communities of the knowledge and agency that *is* more effective. This is not a discounting of medical science: far from it. It is more akin to a critical evaluation of potential and probable efficacy.

One of the most interesting questions that can be asked, I think, is "is a person who knows the dominant or authorised health care action, but chooses *not* to take that action, health literate?" Such a question draws attention to the underlying presupposition of health literacy,

despite putting adjectives like “interactive” and “critical” in front of the phrase: that of its reliance on compliance. Further, when such a notion is built upon an essential assumption of compliance, what happens to those who *choose* to be ‘noncompliant’? There are a wide range of examples that can be given in this respect: for example, those who know the prevailing medical and health advice about obesity (noting, of course, that even that notion is not nearly as concrete as it might seem) and choose to eat more, eat poorly, not exercise, be sedentary, and so forth. There are the smokers that do not attempt quitting, and parents who avoid vaccination. There are people who don’t wash their hands after going to the bathroom, and those who don’t adhere to the customary Food Guide.

I could continue this list for quite some time, but the point I am trying to make is this: what *moral* status do we assign those actions and, by extension, those people? In much the same way as we expect people to succeed in school environments (or go to great lengths to help them succeed), the ‘we’ of the medical and health systems have the same expectations of citizens with respect to their health and wellness actions. We are *expected* to learn, to take advantage, to ask questions, to do what we’re supposed to, because *what kind of person would not want to live healthily, and without pain or disability, for a very long time?* And much of what underpins health literacy is this moral imperative, whether or not is ever openly declared.

I think it is provocative, as well, to consider what the prevailing moral climate would be if, should a person live unhealthily, in pain and disability, and for a very short time, *by choice*, and that choice caused *no economic or other hardship to society*. In other words, if productivity wasn’t an issue, and a community didn’t have to face the realities of a life lived under those circumstances, socially or financially, would governments (and individuals) still care? I’m not sure they would. Some may retort that, if the individual doesn’t care, then why should the rest of

us? Fair enough, but then how do we account for the vast resources spent trying to get people to know and care? Is it mere benevolence, duty, or a more insidious compulsion towards productivity and cost-effectiveness? It is worthwhile to consider.

Health literacy, almost by definition, presupposes a world where there is a moral impetus to ensure individuals and communities are ‘healthy’, and by that, I mean *productive* and *un-costly*. But who is doing the ensuring? The particular art to health literacy is that it turns the onus towards the individual, which the state then supports through infrastructure and health education. It all begs the question: how far are we willing to value ‘independence’ and ‘free will’? Only as far as it doesn’t affect others? How do we understand or define that?

As a mother – and then as a patient –, all of these questions became twisted and turned and virtually impossible to tease apart. Health literacy, if taken at face value, promises to enhance the chances of one’s offspring surviving and thriving by making the individual primarily responsible for recognising and then acting upon those factors that affect survival and success, and *relying upon modern biomedicine* in doing so. Such a primal truth – that really we’re just trying to survive to reproduce and ensure that progeny’s reproduction – is not spoken aloud very often, except on the BBC’s nature programs, and those are the *animals*, not the *humans* (though the distinction is not nearly as clear-cut as one might hope). Throughout human history we have undeniably been driven to push our progeny forward into time and space – it is what creatures do. What has changed, of course, are our methods and our ranking system (in terms of who is ‘worthwhile’ to continue reproducing), not to mention the tools we have at our disposal for such endeavours. We’ve tried public works, and health promotion, and health education and social marketing, and now we’re trying the health literacy angle. We’ve simply put a new name to a

face we've known for millennia, though I do not agree with Tones' (2002) assessment that health literacy is the *same* as health promotion, only that they are *related*.

I suggest that there are three 'tracks' in health – at times they cross over or merge, and at others, they remain separate: wellness, illness, and injury. Further, there are (at least) two subjectivities for each of these literacies: self and other. It is perhaps best to envision these in a matrix (Figure 2): In doing so, it becomes possible to see states of being “self-wellness health literacy” or “other illness health literacy” as separate entities. The type of health literacy employed for ‘self-wellness’ (or taking care of oneself independent of illness or injury) can differ significantly from the type of health literacy necessary in ‘other-injury’ (managing a child’s broken limb). Undeniably, there are shared elements: but it is incredibly difficult, perhaps even possible, to develop a shared definition of health literacy that can account for the myriad subjectivities and conditions manifest. Any attempt slights the subtleties.

Even if we were to assume that the above model moves us towards a more holistic understanding of health literacy-as-lived, there is a need to acknowledge that someone who is deemed “self-wellness health literate” can be so in a range of areas and in a matter of degrees. This person may know a great deal about breast self-examination and annual mammography, but know virtually nothing about influenza and the benefits and drawbacks of vaccination. This is, of course, not to say that this individual can't access the information – it is often more a matter of not knowing what one doesn't know.

Nutbeam (2000) proposed “Levels of Health Literacy” that might also be incorporated into the above model, offering a means of attending to these intricacies. Recalling our earlier discussion, Nutbeam proposed three stages: *functional*, *interactive/communicative*, and *critical* health literacy. *Functional* describes the level where a person can take in basic health

information and act upon it, learning about vaccination, and then making an appointment and showing up. In this level, the individual isn't likely to go out searching for the information, nor

Figure 2 A health literacy matrix

		Subject Position	
		Self	Other
Type of Health Literacy	Wellness	Wellness	Wellness
	Illness	Illness	Illness
	Injury	Injury	Injury

does she tend to ask a lot of questions. Information reaches these individuals through the community, through other medical encounters (such as with a doctor or public health nurse), and social marketing (such as television and radio awareness campaigns).

Interactive health literacy manifests when an individual begins to ask questions and searches out information beyond what is immediately presented. In the example of vaccination, this person might ask a number of questions of her doctor and public health nurse about the side effects and manufacture of the vaccine, and search for further information about vaccines and their success rates in other information sources, primarily locations like the Internet.

Critical health literacy, as envisioned by Nutbeam, constitutes a state where an individual does take in the information presented by authorised sources (social marketing, medical personnel, etc.), but does not necessarily stop at the ‘face value’ of the information, even after pursuing general queries. These individuals are likely to pursue deeper understanding of the procedures, treatments, medications, protocols, side effects, alternative treatments, long-term outcomes, politics, and so forth, which a given approach might encompass. They may challenge orthodoxy and authority, advocate for systemic change, and provide fellow community members with an alternate layperson source of information and advice. Pursuing our vaccination example further, an individual with critical health literacy around vaccines can point to a variety of resources for further information about vaccinations (for and against), she can evaluate the credibility and validity of the evidence presented by various parties, and she can communicate her position and knowledge in social situations that may affect others’ positions on the issue. Nothing in this understanding predicts or ensures what stance on vaccination this person will arrive at, and is thus furthest from a compliance-based model. This type of health literacy is complicated, to be sure: once an individual crosses over from mere follower or clarifier, into

examiner and (perhaps) leader, and such an individual does so without the benefit of status conferred from formal education and positional power, the opportunities for conflict and complexity abound.

Finally, there is an avowed state of *illiteracy*. But what does being *health illiterate* actually mean? In the above example, would someone who is health illiterate with respect to immunisation be someone who doesn't know about vaccination? What about someone who knows about vaccination, but doesn't undergo it? And what of the instance where someone *knows* about immunisation and not only doesn't get vaccinated, but advocates *against* immunisation?

Regardless of the answers we give to these kinds of questions, it should hopefully be apparent that, for any one person, there is an array of potential health literate realities, dependent on the subjectivity (self/other), the nature of the health issue (wellness, illness, injury), and the level of health literacy (illiterate, functional, interactive, critical). One individual can be other-injury-illiterate with respect to broken limbs, at the same time as she is self-illness-interactively health literate with her Type I diabetes. Can health literacy ever be pinned down, let alone achieved, under such circumstances?

Of course, you would be correct in pointing out straightaway that the vast majority of people neither know about, nor necessarily care about, the types of theoretical categories that I am presenting. I am not advocating an educational campaign that introduces individuals to them, either. Can you imagine a future where someone looks at a situation and says, "Well, it's obvious that I'm self-injury functionally health illiterate when it comes to Band-Aid application, because I keep forgetting to keep the pad sterile, but I'm other-illness critically health literate when it comes to chemotherapy, because I've just helped my father through cancer treatments"?

No, my point is more that any honest appraisal of health literacy requires a hard look at what we are expecting of our selves and others, not to mention our systems and our culture(s), when we start to measure, assess, intervene upon, and so forth, notions of what is now being called ‘health literacy’ across a number of healthcare disciplines and policy moves. This is even more critical when we consider that the health care system, which has historically taken upon itself the definition and treatment/management of wellness, illness and injury of individuals, is trying to devolve these roles back to individuals, for myriad reasons. By the standards set forth currently in the Western biomedical context, a massive mobilisation of resources – time, money, people – would have to occur in order to get everyone to this magical (and ephemeral) broad designation of ‘health literate’, even if it is limited to *functional* health literacy.

This devolution amounts to making the expert discourse(s) in health literacy (which is to say the Western biomedical/scientific model of the body) a matter of popular adoption, and with that adoption, making such discourse(s) a matter of *cultural* literacy. Hirsch, Kett & Trefil as much as says this, in their preamble to the Medicine and Health section of the hugely popular ‘*Cultural Literacy*’: “most of the words in this section [Medicine and Health] are frequently used without explanation in the mass media, and hence should be part of the vocabulary of the culturally literate” (2002, p. 546; see also Kirsch, 1987). Therein follows 40 pages of vocabulary with definitions, ranging from adipose tissue (p. 547) to circadian rhythm (p. 554) to parathyroid glands (p. 574) to zygote (p. 586). So, while individuals may not *want* to be ‘culturally health literate’ in the Western biomedical model (or at least not to the degree prescribed by health literacy discourses), they may have no choice, insofar as being able to converse in the dominant health language (Aronowitz & Giroux, 1991) at those moments when these same individuals need to access the systems in place.

How far, then, can we take notions of health literacy and being conversant in the dominant health discourse(s)/cultural health literacy model? I don't really want my surgeon asking me which kind of scalpel I prefer, nor do I want the anaesthetist to consult me on the particular mix of drugs used to put me out, and keep me out, in a surgical situation, for example. I *do*, however, need to be a part of discussions as to whether surgery is necessary, what the alternatives are, what the procedure entails, what the recovery looks like, and what the side effects and/or risks might be. All of this takes time, and it takes a desire on the part of the surgeon *and the patient* to connect: a real conversation between two people (or more, if the situation is one of caring for the 'other') about what it is that is about to occur (potentially) to each. Is this health literacy, or empowerment, or clear communication, or something else?

There are a number of mitigating factors to be considered when exploring what health literacy can and does and might mean, many of which I have either hinted at or spoken to directly. None of these operates in isolation, and it is somewhat misleading to list them linearly, but for the purpose of clarity I will use the convention. My brief notes and observations are as follows (and all of this is declared within the proviso of critical theory – in other words, I cannot possibly unpack or trouble all of these factors, nor am I suggesting that I am absolved, by my admissions herein, of cultural hegemony). That said:

Culture. The cultural context(s) that an individual hearkens from will have an enormous influence upon how they regard health, what get defines as illness or injury or wellness, and what constitutes 'health literacy' – this holds just as true for a layperson as a clinician. Despite the notion that globalisation is leading to homogenisation (and certainly, while systems would prefer such minimisation of difference), diversity still abounds, at least in my community, as any trip to a health care facility will attest. Far too often, lip service is paid to culture, when really what is

desired is *not* a culturally-appropriate form of health literacy (e.g. using food as medicine, or recognising that physiotherapy at a clinic is not possible), but rather a culturally-appropriate way to gain compliance in the health factor in question (e.g. ultrasound protocols, medication compliance, dietary restrictions, and so forth).

How far do you take such an argument? For let's be honest: while medicine is trying to be more culturally inclusive and accessible to those culture's that are continually joining the fabric of our North American society, there must of needs be a limit. At the end of the day, no Western doctor is likely to convert to Ethiopian beliefs about making slits in the eyelid that allows blood to flow into an infected eye as a cure. No more than they are going to prescribe coining to their Khmer patients. Certain cultural treatments that they (Western medical personnel) regard as doing no further harm may be recognised and allowed, or at least tolerated (Graham, 1997; Tea, 2010), but the ultimate goal is to create health literacy in these individuals, which means a fundamental paradigm shift to a Western model of medical diagnosis and treatment (Putsch, III & Joyce, 1990). Is there any way out of this conundrum? Is there any system that can make such vast differences work?

Language. Related to culture, the linguistic community(ies) that a person belongs to will have its own lexicon that describes states of health and wellness. When those lexical tools differ from those used in the establishment charged with 'educating' for health literacy, a number of things might occur – misuse of terms, misunderstanding of terms, or even complete breakdown in communication (Bridging Refugee Youth and Children's Services [BRYCS], 2011).

There are at least two additional considerations under language that need to be addressed: the first is the reality that the specialised terminology used by those operating within the dominant health and wellness culture (as experts) often differs greatly from those used by the lay

community (e.g. cholesterol, tachycardia, femur, obesity); the second is the assumption that native speakers of the language that the dominant health and wellness discourse is carried out in (in this study, English) will necessarily share the same definitions of commonplace terms is also (occasionally) incorrect, e.g., influenza versus ‘flu’.

Recently, CBC Radio aired a *White Coat Black Art* episode (2013), where host Dr. Brian Goldman was interviewing Eugene Mondor, a Critical Care Nurse, on DNRs (Do Not Resuscitate Orders). The conversation turned to the nurse’s role in reinforcing the doctor’s messages, which includes translating ‘doctor speak’. Mondor told of a recent event, where a doctor entered a room with the patient (in ICU) and his family. Here is what Eugene related, beginning with the doctor’s words to the patient’s family:

“He’s got Chronic Obstructive Pulmonary Disorder, we can’t do anything more for him, our plan at this point is get him wheeled from mechanical ventilation, we’ll get him buffed up as much as we can, as crisp as we can. We’re gonna send him out to the ward, and then our plan is is that he would be a ‘no code’, and we would not readmit him to the ICU because we have no more therapy that we can offer.” Physician gets up, he asks, “Is there any more questions?” of the family, and the family says, “No, we’re OK.” So, as a Critical Care Nurse, I stay behind and I say, “Do you have any questions?” His wife turns to me and she says, “Well, I’m just wondering, when’s he going to get his lung transplant?” And I’m thinking, ‘She probably lost the doctor when he came into the room and said “Hello.”’ (19 m 50 sec into broadcast)

Similar to the manner in which my husband was informed of my condition early on, the unique combination of the highly specialised lexicon of the physician and the physician’s idiomatic turns of phrase seems to not only be the only language that it is *possible* to speak of health in, but

it is also the only language that is *desired* to be spoken in – and you, as the patient/parent need to learn their language. Long before physicians become physicians, they are people with, arguably, lay lexicons. No matter how latent those vocabularies are after medical school, they ultimately still possess them, and it is of great concern that physicians appear to continue to use medical jargon as both a buffer and a tool of power over those that they would have become ‘health literate’ when, with little effort, and perhaps a small pad of paper to draw pictures on, much might be accomplished. Plain language documents are very *du rigueur*. What about plain language medical professionals? (and I will freely admit that I have met some in my time – but not nearly enough).

Religion. Tied to culture, though not always fully defining of the culture, religion often tells us about our body’s (and our soul’s) place in the cosmos, relative to human intervention. Whether health/wellness is something that we believe we have free will to influence, or whether it is something that is endowed (or not) by the gods, has an enormous impact upon the kinds and degrees of medical intervention (or health action) that we think is possible or ethical. Even within the dominant health discourse in North America, debates abound around euthanasia, abortion, vaccination, blood transfusions, and so forth. While not always strictly connected with a particular religious outlook (e.g. Catholicism, Islam, Judaism), at root our beliefs about our connection to the spiritual realm dictate (in whole or in part) our relative receptiveness to health and wellness messages (and thus constitute our particular ‘health literacy’); from the perspective of the healthcare provider, this affects how receptive we are to messages and actions related to our health (physical and otherwise) (Abdul-Aziz, 2009), and subsequently ‘health literacy’.

Currently (October 2013) there is an outbreak of measles in the southern Alberta region centred on the prairie city of Lethbridge. As of October 30th, CBC Radio One reported that there

were nine (9) confirmed cases of measles, and many more expected. Data indicates that roughly 61% of the eligible population has been vaccinated at this time, which is significantly below the 85% required for ‘herd immunity’ (*Homestretch*). One of the most common reasons for *not* vaccinating children stems from religious beliefs. A CDC report (Arciuolo et al., 2013) highlights the virulence of measles and its connection to outbreaks in populations that remain unvaccinated due to religious reasons (in this case, the orthodox Jewish community in Brooklyn, NY); a related *Measles and Rubella Initiative* web post (a joint effort of the American Red Cross, the CDC, UNICEF, the United Nations Foundation, and the WHO) outlines a number of other examples from 2013 alone.

Education. Much of the discussion around health literacy began with concern with literacy scores, and there is undeniably a connection between education and literacy (though, it would seem, not as clear a one as one would hope). An assumption that one’s *level* of education is somehow related to one’s health literacy – in other words, if someone is a lawyer, for instance, they are more likely to be health literate than someone who (again, for example) is a mechanic – is a dangerous supposition (Speros, 2005). Equating years of education with general literacy, or even more hypothetically *specific* literacies, like health, is potentially harmful to all.

What seems to be more likely is a connection between health-related education and/or experience and health literacy. As self-evident as this might seem, it is important to remember that health-related education and its connection to health literacy is a culturally-driven education: in other words, when you experience a ‘health education’ (whether as a professional or as a mother at the public health nurse), the form of ‘health literacy’ you obtain is *not* one that critically evaluates relations between power and knowledge and education (in no way whatsoever does it aspire to Freire’s *conscientização*). The education is designed to teach the

right way to view or do things, resulting in ‘informed compliance’ (Graham, Carlson, Sodergren, Detter, & Labbe, 1997; McGuigan, 2010), even as medical professionals. One and all operate within a pre-formed realm of action and reaction.

During an *Airplay* discussion on CBC Radio One (November 4, 2013), Dr Brian Goldman outlined the problem with No Shows. These are individuals who make appointments, but don’t keep and don’t cancel them. Those who do it regularly are known as ‘Chronic No Shows’. A number of reasons are suggested for this behaviour, including patient (forgetting, not having transportation) and physician behaviours (time mismanagement that leads to disengaged patients, continual rescheduling), and a number of implications for the health system and the health of others are detailed. The most interesting point that Dr Goldman makes, at least for this study’s purposes, surrounds Chronic No Shows as a pattern of behaviours that are indicative of non-compliance. Lumped in are those who don’t follow treatment advice, and those who don’t take medication or show up for scheduled tests. He doesn’t take up *why* these patients are ‘non-compliant’: only that this pattern of behaviour is undesirable. But the subtext is clear: no shows are *not* health literate, because if they were, they would be compliant with the scheduling.

Beyond this, there is a distinct form of health education (leading to a specific form of health literacy) that derives from experience. In other words, you learn about cancer (to some degree) by *having* cancer or *caring* for someone with cancer. Of course, if you have many years of education, it is possibly *easier* for you to digest the bits of microbiology you are faced with, but there is no essential predisposition that a Bachelors’, Masters’ or Doctoral degree gives you to deal with such things. Further, you learn what is in your environment: whether you are moving outside your class structure (and let’s not be delicate here: class does exist), your cultural milieu, or your language capabilities, you are in a situation where you will have to learn

something new (and not necessarily easily or comfortably). Many of us (if not most) will attempt to hang on to what we already know for much longer than is healthy or wise.

When travelling in Greece and Italy three years ago with my family (the boys were five and two) and my mother, I became very ill in Athens. I actually don't remember much beyond the burn of the acrid air in Athens in my lungs – the rest is a blur. My husband was too overwhelmed by everything, and I don't think he realised how sick I was (or where to even begin in trying to get help for me). When we arrived in Firenze, it was my mother who took ill (I was by now improving). Part of her symptoms included an intense ear infection. We were slated to fly back to Canada in five days. A week earlier I had been the very ill person, and nobody in our group (and the first week there were about twelve others travelling as part of a wedding party) did anything, other than my new sister-in-law's aunt, who offered to dose me with her cough syrup with codeine (apparently she never travelled without it). But here we were, now a party of five (including two small boys), in a foreign country, in a villa where virtually no one spoke our language.

I couldn't let my mother fly, and I told her so. She was already angry with me for a variety of other travelling infractions, so this didn't help matters. I told her I was going to speak to the villa's manager, a woman named Costanza, about finding a local doctor. She made a few phone calls, and told me that, while it would cost me, she had found a physician who would come to the villa that Sunday afternoon to assess my mother. I told my mother the plan, and vowed to return later that afternoon (after searching out food – turns out you can't really buy groceries on Sundays where we were) in time for the physician.

He was a bit early, we were a bit late: she was a lot mad. When I walked into the villa, I was able to watch my mother interact with the doctor, which is to say they were *not*

communicating. In what can only be described as Italglish, he was trying to take a history. My mother was taking her frustration out on him, and was obstinately not answering. He finally (in his own frustration) turned to me, and starting speaking Italglish. I responded in English. This heartened him, and he attempted more. Between the two of us, we cobbled together a history; he did a brief exam on my (now fuming) mother, and wrote a prescription. He explained (twice) how to take the medications. I signalled I understood, paid him in euros, and ushered him out.

When I turned back to my mother, she looked me square in the eye, and said, “Don’t bother getting that prescription filled: I’m not taking it.” She stomped out of the room, locking herself in the bathroom. Jack, standing beside me by now, looked up at me, and asked, “Why won’t grandma take her medicine?” I think I probably said something about asking his grandmother himself, or perhaps something about his being more mature than she, or something else equally uncharitable.

Despite her hostility, we found a pharmacy, and I once again muddled through an exchange. Bag of drugs in hand, we walked back to the villa and I (I am somewhat ashamed to admit) had Jack deliver it to my mother. Later, while sitting outside the villa, Costanza approached me and asked how it went: After thanking her for her invaluable assistance, I mourned the excruciating nature of the whole matter. She patted me consolingly on the shoulder, and assured me that her father would have responded similarly, because it was anathema for a child to know the parent’s medical issues, much less be privy to an actual exchange with the doctor. This connection, between two women, on opposite sides of the planet, barely intelligible to one another, over our *parent’s health* was profound for me.

Now, I hadn't considered this: was *this* the cause of my mother's reaction? I still wonder a bit, but truthfully I think it has far more to do with feeling shame and a sense of powerlessness. She was sick, in a foreign country, couldn't speak the language, and didn't understand the culture.

However, there is something else I wonder, and it has a direct link to education, hence this story's place here: the previous week, no one had lifted a finger to help me (and believe me, I needed it), yet here I was using all of my faculties to attempt to aid my mother. I would have done the same for my children or my husband. Why? Wherein does the difference lie?

A few thoughts come to mind. The first, and most easily picked upon, is my education. My years of formal education outstripped anyone in our party (including my husband, a PEng with an MBA). I am interested in health, and other countries and cultures, and I read extensively. I have friends from all over the world, and I learn a great deal hearing their stories. I had no especial ability with Italian (though, sadly, I was the most 'fluent' in the group, which isn't saying much). So, while I wasn't educated for this endeavour, having succeeded at education, and the concomitant literacy that I possessed, *empowered me* to feel like I could actual do something in this foreign situation. It wasn't so much that my education made me *health literate*: rather, having had previous success in educational endeavours (and new situations) predisposed me to thinking that I could perform equally effectively (with caveats) in this new situation. Knowing others' stories (and having a bit of common sense), I figured "Italians have doctors. I'll speak to an Italian." Oh, but there's one other harsh fact that I must now admit, as I write this: I had money. Money I could spend on health; and I was *willing* to both look foolish in the asking, and like a rube in the amount of money I paid (which I will admit was exorbitant by my pampered Canadian standards).

Socioeconomic status.

McGuigan (2010), in discussing Ethiopian and Eritrean immigrant diabetes education, pointed out that, for these individuals, in their home countries, “health care is far more limited and awareness of diabetes is far less (p. 4). Further, the ability to self-test blood glucose levels (as is the norm in North America) is not readily available, as test strips are in short supply. She shared the words of one of her Ethiopian interviewees: “Health care is a luxury back home. You go to the clinic when you are sick and expect a short course of medication that ‘cures’ the problem” (p. 4). Conceiving of a lifetime of illness that must be managed is foreign. In many countries, the standard is simply one where, if you get sick, there are two options: get better or die. Either way, the problem is solved.

There has been much discussion (and research) around the idea of ‘low health literacy’ being related to lower socio-economic status: specific populations have been identified (e.g. single mothers, teenage mothers, immigrants, seniors, Indigenous, Latino and Black Americans, those with less than a high school education) and detailed health literacy interventions developed (e.g. plain language materials, multimedia resources, translated materials, homecare visits, ‘Ask Me Three’ protocols, public health nursing, community nursing) (cf. Act II). There is a great deal of value in such a “social justice” perspective (though it can be argued that such elaborate strategies are still missing the point – they avoid the systemic factors that lead to inequity in the first place).

However, as this study has sought to point out, the problems with ‘health literacy’ are not just those associated with gaps between lower SES and low health literacy (or functional health literacy). The situation is far more intricate, and it is by no means limited to public or clinical health, or socioeconomic status (or any of the other factors). There is evidence that class-status

impacts views of agency and health (Blair, 1993; Lupton, 1997; Popay, Bennett, Thomas, Williams, Gatrell, & Bostock, 2003). For instance, working class individuals generally seem to attribute health status, and health care, to extrinsic sources. The world makes you sick and doctors make you better. The higher the SES, the more the individual is likely to view matters intrinsically. Self-inflicted health status is matched with self-efficacious healing behaviours. It is not, in either instance, that individuals are more or less likely to be compliant – rather, the difference lies in how they regard the disease mechanisms and their own agency in effecting positive health change (with or without medical intervention).

There is also the painful reality that knowing what you're 'supposed to do' for your family's health and wellness, and lacking the resources to meet those needs (leaving aside whether those needs are real), you face the knowledge that you fail on at least two levels. It does little to put up posters and hold parenting workshops advocating 'eating fresh fruits and vegetables' when you can afford no food, or reprimanding populations for not using proper hand hygiene when there is no fresh water, or no money for soap (Dutta-Bergman, 2005).

Once, while travelling in the Dominican Republic in my late twenties, I asked about the heaps of garbage scattered about the beautiful countryside (while my travel mates muttered under their breath about the filthy living conditions and shameful pollution from the comfort of their air conditioned tour van). The answer, my guide told me, was simple: the people of the DR couldn't afford garbage bags, and even if they could, there was no state infrastructure for the collection and disposal of the bags (which is to say, nowhere designated to bury it, or send it elsewhere on a barge). So, while the citizens were no doubt aware that it was unhygienic to live amongst their refuse, there wasn't a great of choice available under the current civic conditions.

As this preliminary, and rough, sketch of health literacy's mitigating factors hopefully elucidates, the possibility of finding a common thread running through is unlikely. All of the ways and means of understanding and using health literacy are deeply complex and complicated. Little wonder that there is no agreement amongst practitioners and policy-makers alike, even before the individual's experiences are factored in.

So where does all of this leave the notion of health literacy, and any hope of further understanding? As I came to the end of the fourth Act, and set out to capture conclusions, I was pulled up short. Partly out of exhaustion, partly out of confusion, I found that I had decided that all that I had done amounted to nothing: health literacy didn't – *couldn't* – exist. It wasn't that I agreed with Tones' assessment that health literacy was merely health promotion in different packaging, and it wasn't that I felt that there was no *value* in the idea or pursuit of health literacy. Rather, it was more a matter of feeling overwhelmed by the diverse and disparate theoretical and operational definitions of health literacy in the various realms of the health and wellness encounter (both from the individual's and the institution's level). There was no one thing that they all shared in common, and therefore they could not share a common understanding or definition. I had inadvertently taken the essentialist's tack in analysing my data (Beardsmore, 1992, p. 135).

But then I was directed towards Wittgenstein's theory of *family resemblances* (1953/2001). While I had encountered this concept very early in my doctoral program, it had simply faded away with time and circumstance. When it was suggested to me that what I had, in fact, discovered was a *family resemblance* between the assorted notions and applications of health literacy, I was startled. In an instant, the thing that I had been searching for was in front of me.

Suddenly, I could see that, amidst all of the literature on health literacy, and the myriad instances I had experienced, while there was no singular definition of health literacy that could be applied by all individuals in all situations, there was a *web of interconnected ideas* that tied health literacy understandings and applications together. However, with every sector or discipline advocating their own particularly nuanced version of health literacy, and none agreeing (or sometimes even knowing the other was thinking and writing on the topic), it opened the door for others outside the immediate confines of health literacy to suggest that such a thing does not exist (the conclusion I initialled arrived at). In effect, the focus has been *too specific*.

But stepping back, and regarding the body of work I have both covered and created, it seems quite clear that there is affiliation between all of the health literacies I have encountered. I can recognise clinical health literacy as an instance of ‘health literacy’, in the same way as I can regard critical self wellness health literacy as a type of health literacy. They may not share all of the same characteristics, expectations, environments or levels of aptitude, but they nonetheless are identifiable occasions of something we call ‘health literacy’.

This is where Tones (2002) and I would differ: I think it likely that he would look at the previous paragraph and declare that, while I was on the right track, I wasn’t quite there yet. It’s probable that he would suggest that health literacy falls within the *family resemblance* realm of health promotion, or perhaps even health education. I can certainly see where he would arrive at this conclusion. By extension, one can broaden the scope until everything is encompassed within one family, for instance ‘health promotion’ or even ‘health’.

But in practical terms, what differentiates health literacy from health education or promotion is the *direction of responsibility*. Health literacy, above all else, connects the idea of *learning* about health care (whether it’s wellness, illness, or injury) and then *acting upon* that

learning. Whether that learning hearkens from the doctor, social marketing, one's family, one's culture, research, experience, or any other realm, the precept is the same: you learn/are taught about these things so you can then *apply* what you know.

Returning to the various experiences and reflections offered (primarily in Act III), it can be seen that health literacy became conceptually problematic to me when I expected that this linkage – the 'learn/taught' then 'act' (and be assessed) – would look and feel the same in every instance where I was called upon to develop and/or enact health literacy. When I stepped back and regarded the *family resemblance* as the *informed process (undertaken by an individual or community) leading to something recognised as 'health' (for that individual or community)*, rather than a set of specifying requirements (like content, provider, nature of the illness, and so forth), I became aware of the web.

I am not suggesting, as Stone (1994) fears, that, given such a 'definition' of health literacy that we abandon any further exploration of what health literacy can and does (or might) mean. What I *am* offering is an understanding of the *family resemblance* contained within extant definitions, usages and experiences of health literacy (or "complicated network of similarities" (Wittgenstein, 1953, p. 27)) in order to move the discussion to another level, one where the focus is less on jockeying for definition dominance, and more upon appreciating the intricacies that are inherent in asking individuals/communities to process and enact external expectations around 'health'.

Right now, notions of health literacy point us towards very important questions. For instance, how do we balance individuals' conceptions of health in a diverse society with a less-than-diverse and –flexible Byzantine system? How much are we willing to pay to keep people alive (especially when it can be argued that behaviours, in some cases, lead to the outcomes that

then require health-saving measures)? How can we, in good conscience, council people to maintain healthy lifestyles and lifestyle choices (evidence of health literacy) when the most basic, systemic elements of health and empowerment are not freely available to all (and we cannot hope to determine on a case-by-base basis where each person stands)? What right do we have to mark individuals as ‘health illiterate’ when the ground keeps changing under peoples’ feet? How can we ask doctors to spend more time with each patient (to enable their health literacy) and expect the same doctors to keep up ‘volume’? How can we strip people of the agency and folk knowledge of self-care (their former health literacy) and then complain that people keep showing up to emergency rooms or clinical practices with things that can’t be helped in that setting?

This is what ‘critical’ thinking about health literacy has given me: a lot of very hard questions that keep me up at night. And no real answers. My consciousness has been raised. I finish with Gergen’s prescient words

Given a range of competing constructions, and sufficient stakes in the outcomes, there may be brisk competition over whose voice is honoured. Whose voice prevails in a sea of alternatives may be critical to the fate of the person, relationships, family life, community, and in a significant sense to the future of humankind (1989, p. 73)

Parting Words

Just as it was in the beginning of this work, it has freshly finished storming outside. The world is once again muted and softened, the white cloth of snow masking much of what lies underneath. Because I know this world, I can tell what lies below. The moon, bright and full, has drawn the colour from the landscape, leaving behind a silver sheen. Things have returned to that half-reality that I love about this time of the year.

My son is sick again; I am struggling to finish my work; my family calls nearly daily with their various concerns; every time I turn the radio, the television, or open a magazine, I am faced again with innumerable bits of knowledge and fragments of questions that have increasingly defined my life these past 7 years. I don't have the answers, I can't know all the information, there will always remain things that lie below that I will never see clearly.

And that is all right, because "Knowledge is not primarily facts or dogma, but experience, made stable by integrity, and by being part of a whole. Any human activity, if pursued selflessly, can lead to profound understanding" (Yawar, 2010, p. 546)

Epilogues Aren't Just for Shakespeare

The interesting thing about engaging bricolage as a tool for thinking about something is that you can never predict the outcome. Sure, I wanted to explore the ideas around health literacy from the standpoint of a mother and a patient (and, of course, that's my none-too-exciting title). At the end of the whole process (or, at least, at the point where I drew my line in the sand), I looked back, saw one thing, then saw another. The first was that I saw no single definition; the second was that I saw a series of family resemblances. But because of the nature of *how* I approached the work, and in particular the choice to capture the stories in narratives, something else has emerged. Perhaps you've already picked up on it: power.

Oh, I know: it's a ridiculously overused, bordering on trite, word. And maybe that's why I didn't go in that direction (at least not explicitly) within the work. Possibly it's because that, in the vernacular of autoethnography, I needed to have created my distance in order to have perspective. Or perhaps I simply wasn't turning the crystal in the direction needed to see the idea clearly. Whatever the reason, it is only now, when I thought I had 'finished' the work, that I see this whole new possibility within my study.

Power, or the ability to influence, control, dominate, or otherwise exert authority over a person, population, situation or notion, underlies *all* of the discussions about health literacy. This is not to say that it is fundamental to the definition, not in the way that some like to envision it, as "empowerment". Certainly there are visions of this kind of health literacy, and most assuredly there are advocates. But there are many conceptualisations of health literacy that have nothing to do with empowerment (for the patient or consumer), but rather more to do with solidifying and even enhancing the power of the medical establishment. Take, for instance, the rhetoric of compliance: there is no sharing of power with the patient. There is no discussion, no

questioning, no challenging, and certainly no abrogation of the medicine's fundamental authority.

Just today I visited my family physician, where she shared a communication she'd had with an endocrinologist regarding my "case". Earlier this year (February 3rd, 2014, to be exact), I had my most severe (at least, numerically) pancreatic attack to date. My lipase was registering at 1461 mm/L. You'll perhaps recall that the "norm" falls between 0 and 160 mm/L. Now, not being one to brag, I still must point out that this represents a 9-fold increase in lipase levels, *taken from the top-end of the range*. Unlike my previous encounters, *everything* was being done properly: food, exercise, stress, medication, all "Therapeutic Lifestyle Changes" were being honoured (and not just in the lip-service sense). Even this dissertation was done (though not yet defended).

So, when I presented at the ER with such grossly elevated lipase levels, along with an elevated white blood cell count, there was no way to account for my situation (did I add that, at no time, did anyone run my triglycerides, despite my case history?). After a few days, I was released, none the more knowledgeable of *how* I'd gotten there, and *how* I'd avoid such a future outcome.

Which leads us back to my visit to my physician today. In the absence of any clarity on the situation, she'd thought it best to send in a referral to the endocrinologist. She went on to inform me that the endocrinologist had responded that he couldn't do anything for me, that I would best be served by *nutritional consultation*. Never mind that my case file is full of such accounts, along with the concomitant acknowledgement of the breadth and depth of my nutritional knowledge and facility. Apparently yet *another* visit to the dietician will solve all that ails me.

But what is *really* interesting about this story is what happened two weeks before I went to see my doctor. I received a call from the endocrinologist-in-question's office, wherein the clerk tried to book me into a nutritional consultation. I asked her why, and I also asked her if I was *required* to see the dietician prior to the endocrinologist. She informed me that the doctor *preferred* that this be the order of operations. I informed her that I'd done that innumerable times, and that I could quote chapter and verse the authorised nutritional information, and that I felt it was a waste of everyone's time. I told her to call me back when the doctor was ready to book, and she basically hung up on me.

Now, I don't know if my doctor's message pre-dated this exchange, or post-dated it, but let's consider both scenarios for a moment. If my doctor received the message *before* I had the phone call, then the endocrinologist never intended to see me, and assumed that whatever I was told I would do (meaning, if I was told I needed a dietary consult, I'd get that, and there would be no forthcoming specialist appointment). Or, if the message came *after* the phone call, either the endocrinologist is punishing me for noncompliance, or tipping his hand that he never intended to see me (despite the clerk's earlier words).

Regardless, this is an interesting exercise in power, I think. While my doctor has the 'power' to refer me (I can't refer myself), she doesn't have the ability to make the endocrinologist see me. While I have the power to decline the nutritionist appointment, I can't make the specialist see me. Does the specialist's office think that my doctor and I won't compare notes? Or that my doctor won't take my words seriously? Did I mess up the whole 'plan' by not being compliant? Any way you slice it, the endocrinologist is refusing to see me. It's one thing to say, "Look, I don't think there's anything more we can do for this patient. Sorry." That I could understand and respect: science is limited. It's entirely another to try to

play games wherein people are told differing stories, and that a “lower down” specialisation (in this case, dietary science) is brought in to deflect the truth, rather than being up front. Of course, there is also the notion that the endocrinologist *really does* think that a nutritional consult is the best step forward, but in that event I have to question a) has he not read my *massive* file?, and b) why would the clerk say one thing and the message another? (Which, of course, brings forth the question of how doctors speak to one another, versus how they communicate with ‘lower’ staff and patients). There is even the very real possibility that the clerk was exercising *her* version of power, but illiterate power insofar as my circumstances, by saying something to me in the phone call that the doctor had never advised (and, presumably, this clerk was involved on some level with the message that made its way to my doctor).

And all of this brings me to a discussion of illiteracy and power. Sure, advocates of health literacy espouse that literacy leads to empowerment, which leads to positive patient outcomes (or just plain human outcomes). But no one seems to be looking at another form of illiteracy – situational health illiteracy, I’ll call it. Over and over again, throughout my work, you can trace instances where the health professional has health *literacy*, insofar as the nuts and bolts of medical practice are concerned, but that same person is flagrantly *health illiterate* when it comes to dealing with whole classes of patients. In my particular instance, my ‘chronicity’, both in terms of my back and my pancreas, is of especial interest.

But, because the health professional has *positional power*, power that we’ve, culturally and collectively, ascribed to their so-called knowledge and work, the situation has become one where their power circumvents their ability to look at what they *don’t know* (and are therefore illiterate in) in relation to what they *do know*. Instead of the practice of “taking a history”, where the only choice was to listen at length and observe closely, we’re being reduced down to

numbers, tiny tidbits of technology, and brief histories. I'm sure the endocrinologist is utterly certain that he is right – based on an extremely brief, and entirely incomplete, picture of me and my situation, and he is, quite frankly, entirely unaware (and probably uninterested in) my chronic condition health literacy.

Much the same thing happens between mothers and the larger society, I have noticed. There has been a sort of abdication of authority. With the advent of the 'expert', mothers have come to increasingly defer their (sometimes, though not always) better judgment and situational literacy to an army of professional 'knowers' that will tell them everything from when their child should say "mama" to when they have bowel movements (and *everything* in between, I assure you).

This has bred fear and uncertainty for many, many mothers, as they continually seek outside sources of information and validation for their maternal practice. I'm not saying that outside information is a bad thing: after all, in our current biotechnical world, it's utterly impossible for any one person to begin to understand all that available to be understood (and that, by the way, includes medical professionals). But something more insidious has happened: mothers have been stripped of generations of maternal (health) literacy. Instead of confidence in how to treat common colds, fears, bumps and bruises, and keeping their children safe in general, mothers (and fathers) are fed a constant diet of fear mongering and anxiety. While you might argue that mothers have the choice *not* to eat of the poisoned apple, so to speak, I think that a Western middle-class mother (particularly one who has been born and bred here) is hard pressed to resist. It is in all the messaging we receive as children, and then as the parents of children.

So, again we see power being shifted, but not shared, to sources external and 'expert' to the person(s) in question. Mothers are 'empowered' to see their doctors, consult the latest

websites, purchase the most current consumables, read the hottest parenting bestsellers. But the message remains the same: power lies in external sources, and your access to these sources means understanding of, and compliance with, the dominant parenting paradigm.

Gone are the days when you call your mother or grandmother to find out what to do about something health-related with your child. Not to paint the intergenerational health communications of days past as sunshine and butterflies, it still seems that, in previous periods, there *was* a respect for and appreciation (and utilisation) of the experience that older mothers brought to the table. Now, you don't often hear a woman admitting she's called her mother (or even *moreso*, her grandmother) for health advice: instead, you hear the scoffing stories of how 'backwards' and 'uninformed' (read: health illiterate) these older mothers are. Never mind the fact we survived their prehistoric parenting.

True, things *have* changed, insofar as understanding of disease mechanisms and biotechnology (e.g. vaccinations, antibiotics) are concerned. But human *children*? I'm not sure the care and feeding of such creatures has changed overmuch in millennia. However, an entire enterprise has grown up around mothers being (health) illiterate, and the power to influence their mothering practice has been transferred to the medical/health professions, and (increasingly) the popular media and capitalist boldness.

All that I have said has been from the perspective of a white, domestically born and raised, educated, class-transitioning, Catholic, able-bodied (mostly!), married, heterosexual, woman. All (except the 'woman' part) puts me into most people's categorisation of utterly privileged. I absolutely cannot know (in this, my home environment) what it is like to be 'other' in the strictest sense. For as much as I feel that power has been given to those outside myself (particularly in the instances of my trying to manage my chronic health issues), when I would

argue that, at minimum, a true partnership would serve all much better, the fact remains that I still have an enormous amount of power simply by being *me*.

Going forward, I would want to explore these ideas: about how my advocacy for myself is aided and abetted by my own personal power and confidence (and communication abilities); how immigrant mothers feel (and react) in this environment of pronounced powerlessness; how doctors (and other medical professionals) can begin to work more effectively with patients such as myself, who have narratives of chronicity that put us into an entirely other patient category, one that will increasingly reflect the majority.

As I said early on: I have many more questions than answers. But at least, now, I have questions that I have never asked before, and that is something new.

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