

Making Sense of My Illness Journey from Thyrotoxicosis to Health: an Autoethnography

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In this paper, I focus on my experience of hyperthyroidism and contend that that being reflexive about one's illnesses can be a valuable healing tool for patients and medical professionals alike. Looking at the tradition of ruminating on one's illness in medical sociology, I characterize two genres, 'modernist observers' and 'post-modernist witnesses'. I introduce autoethnography as one methodological way of being reflexive. The resultant work is evaluated through two lenses: science and art. In health and illness contexts, autoethnography presents particular embodied events with people in time, their social shaping and how these can be seen as emblematic of wider cultural meanings and social trends. After sharing my story, I demonstrate how my experiences can be understood by exploring the notion, sentimental work. While I try to be generous to the reader, I sense that I give voice to my body, connect to others and bear witness to how my embodied identification with others induces dialogical exchanges. My particular experience is revised from a feminist perspective, challenging current biomedical ideas about the negative workings of women's immunological system and indispensability of allopathic medicine. I contend that we should contest outdated medical practices, based on gendered stereotypes of ageing, sick bodies.

The professional eye saw in me only a mass of humour, a sorry mixture of blood and lymph. . . . It occurred to me for the first time that my body, my faithful companion and friend, truer and better known to me than my own soul, may be after all only a sly beast who will end by devouring his master (sic.). But enough, I like my body; it has served me well and in every way and I do not begrudge it the cares it now needs . . .

(Yourcenar, 1951: 3)

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INTRODUCTION: BEGINNING WITH THE PERSONAL

I begin with expectation mixed with fear. It has been some time since I wrote an academic paper. I have just suffered for two years from thyrotoxicosis.¹ This troublesome disease entity attacked my body and robbed me of a vibrant, incisive, sociological, feminist voice. At a deep level, this voice I so love eluded me. My voice has given me hope and emotional sustenance for over thirty years – now this sense of losing it.

When this acute thyroid problem hit my body, I was in a whirlwind of academic activity, editing a book and writing another. I was on sabbatical leave – taking work trips to Finland, Italy and Belgium. On a personal level, my partner and I were grieving – recovering from the deaths of her father and sister, both of which occurred within a week of each other. My partner experienced a health crisis which at first we thought was life-threatening. It was one of the most difficult times of my life. Illness and death were all around. Feeling that I had no space in this turbulent time, I was afraid of living. The emotional pain was almost unbearable. I put on a good face and coped, not noticing subtle bodily changes.² When I did begin to notice, I thought ‘menopause’, reflecting how medical interpretations often percolate into lay ones.

I start with how sociologists think and write about their own illness experiences and the different genres which have a major role to play in a person’s quest for authenticity, while experiencing ‘a loss of self’ (Charmaz, 1983). Next, I introduce autoethnography as a methodological tool for thinking, speaking and writing reflexively about my own illness experiences. While reflexivity is ‘not an epistemological, moral or political virtue’ (Lynch, 2000), it is about existential, embodied identifications with others based on dialogical exchanges. While ‘thinking is like breathing’ and I do it unreflexively, I can *think reflexively* ‘with full awareness’ by making my thinking a ‘full project on its own’ (Braidotti, 2002: 93): I can become a communicative body (Frank, 1995), joining with other ill bodies in a salutation of generosity (Frank, 2004).

While my autoethnography is embedded in contemporary work which makes connections between bodies, gender, illness, health and healing (Clarke and Olesen, 1999; Sparkes, 2003a; 2003b; Sparkes and Smith, 2002; Smith and Sparkes, 2004), it contributes to academic debates which call for more innovative methods within medical sociology (Lawton, 2003) and shows that while chronic illness has a major impact on identity (Charmaz, 1983; 1990; 1991; 1999) and is a radical intrusion into embodied selfhood (Turner, 1992), acute illness is a neglected area of research. I then share my illness story and demonstrate how it can be understood by exploring the notion of sentimental work. My assumption is that being reflexive about one’s illnesses can be a valuable healing tool for patients and medical professionals alike.

SETTING THE SCENE: 'MODERNIST OBSERVERS' AND 'POSTMODERN WITNESSES'

In medical sociology there exists a long-standing body of work in which sociologists ruminate on their illness experiences (Roth, 1963; Davis and Horobin, 1977; Zola, 1982; Frank, 1991; 1995; Adamson, 1997; Rier, 2000; Sparkes, 1996; 2003a; 2003b). Within this work, two related but disparate genres appear: 'modernist observers' and 'postmodernist witnesses'. Notably, these genres are not a strict binary and a few 'modernist' accounts (see Jobling, 1977; Macintyre and Oldman, 1977) hint at 'postmodern' narratives to come.

Modernist observers (Roth, 1963; authors in Davis and Horobin, 1977; Zola, 1982) scrutinize the multiplicity of processes involved in the sick role. I cannot fault them for lack of detail or complex sociological analyses. Nevertheless, when observing their health problems, they treat their illness accounts as alien, revealing an essentialist frame of mind. Their propensity towards fixity in analysing consultation behaviour (Jobling, 1977), hospitalization (Fairhurst, 1977), medical routines (Strong, 1977) and marking time (Roth, 1963) creates the image of omniscient onlooker, satiated with rational, scientific explanations but somewhat devoid of emotions. The body is invisible, but has a fleeting appearance when pregnant ones, lying in examination rooms, are resplendent in clinical functionality (Camaroff, 1977). Additionally, the virile, masculinist voice dominates as privileged male patients bond with their doctors when 'the old school tie is delicately indicated' (Strong, 1977: 48); an ideal patient adopts 'the role of man on the street' (Atkinson, 1977: 27) and the abstract patient is referred to as 'he' (Mapes, 1977).

Taking an autocritical stance to past work in this genre, Zola (1991: 3), a former modernist observer, contends that, 'We were locked into a view of ourselves as patients in the sick role' ... 'Our protest was ... personal not social', and 'nobody but us learned anything'. Zola (1991: 7) indicates 'the sexist bias' that influenced diagnoses and work in the area. Most importantly, Zola (1991: 4) contends that 'medicine's view' of our (the patient's) reality was essentially 'unchanged and unchallenged'. I agree with Zola's call for a new paradigm, bringing the body into medical sociology and for taking up feminism's challenge leading to a new praxis in medical sociology. Implicitly, Zola's makes a distinction between the illness narrations of modernist observers and postmodernist witnesses.

While both genres link narratives with the experience of illness, the postmodernists are receptive to the vagaries of patienthood and lability in ill bodies. They are more open to a medical sociology which moves away from universalistic conceptions of doctors, patients and health and illness experiences towards a 'plurality of truths' (Bell, 2000: 132) that embraces

multiple embodied forms of health and illness representations, replete with uncertainties.

This postmodern turn or more adequately, twist, goes beyond monolithic notions that a single cultural perspective, revealing an irrefutable set of truths to be known exists. That any medical sociologist is able to achieve an understanding of illness experiences outside of specific historical contexts or without recognition of shifting relations of power and inequalities becomes questionable (Bell, 2000: 132) for postmodernists, while this can not be said of modernists.

Postmodern witnesses (Rier, 2000; Adamson, 1997; Sparkes, 1996; 2003a; 2003b; Frank, 1991; 1995) to name a few, bring the body, emotions, participation and existential uncertainty into medical sociology. They do this in such a powerful way that our understanding of the many layered texture of illnesses is shaped by actively engaging with anxiety, despair, disgust and agony as well as triumph, hope, joy and pleasure. Their narratives generate useful ways of creating knowledge about suffering and of grappling not only with the intricate, interior language of wounding, despair and moral pain but also the victory of living an illness (Bell, 2000: 139). They deploy a type of 'anti-narrative' (Scholes, 1980) which frustrates closure, brings performative codes to our critical attention and sees these codes as cultural rather than fixed aspects of human nature. As emotional and vulnerable, they give voice to the structured silence of embodied illness experiences as well as sociological shape to the diverse, complementary and conflicting assistance that the experience of the self and the body bring to health and illness. What do we learn?

Regardless of patients' existential claims-making and physicians' clinical voices, the mutuality of the effects on each other must become visible, if we are to understand the pervasiveness of 'uncertainty' in medical encounters (Adamson, 1997). Rier's (2000) experience of critical illness in an Intensive Care Unit acknowledges that the current discourse on patient participation and negotiation is not relevant to the critically ill. Sparkes (2003a; 2003b) shows the devastating sense of loss when injury shapes a performing athletic body into 'a failed' disabled one. One of the unsuspected rewards of being ill is to tell a story that can transform sheer struggle, survival and revulsion into a significant embodied, social and moral life that is self-authenticating and productive of desire (Frank, 1995).

By giving testimony to what has been traditionally abject in illness accounts, these 'postmoderns' make way for new and perhaps more reflexive, gender sensitive ways of doing patienthood. A major criticism levelled towards this genre is that physicians are demonized, while patients emerge as heroes (Atkinson, 1997). Refuting this claim, Bochner (2001: 148) shows that Atkinson overlooks the power dynamics to which many illness stories respond and the division of control between those who are ill and

those who represent them in narrative. We tell illness narratives because telling not only gives us therapeutic benefits of redemptive understanding, but also the 'political consequences of connecting the body to the self' reveal 'embodiment and emotionality as legitimate mediums of lived experience, inscribing bodily dysfunction with value' (Bochner, 2001: 148). Successful illness narratives require an active and reflexive reader who wants to enter into dialogue with the writer and story (Bochner, 2001) and offer the reader multiple places to stand in the story (Berger, 2001). While autoethnography can be a useful way of telling health and illness stories, it is more akin to postmodernist witnesses than modernist observers.

AUTOETHNOGRAPHY: THINKING AND FEELING WITH MY ILLNESS STORY

Autoethnography is related to the above tradition, but has no allegiance to any discipline (Wolcott, 2004). As a term, it has been in circulation for at least three decades and is defined as 'an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural' (Ellis and Bochner, 2000: 739). Writing in first-person voice (see Katz Rothman, 2005), autoethnographers look back and forth 'first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then inward, exposing a vulnerable self that is moved by, through and resists cultural interpretations' (Ellis and Bochner, 2000: 739). Proponents of autoethnography, such as Carolyn Ellis (1991; 1995; 1999; 2000), Laurel Richardson (2000a; 2000b; 2000c; 2003) and Arthur Bochner (2000; 2001; 2003), share a consensus that autoethnography be evaluated through two lenses, science and art. They bridge the gap between scientific and literary writing and propose new writing practices (Gray, 2004). Within autoethnography, the intention, shape and rapport of the artistic piece emulates the emotional and scientific commitment of a triumvirate: author, story and reader. In 'doing' my illness story, I follow the above insights. However, I am aware that colleagues may use a variety of criteria to judge my work. They may make different interpretations about the meaning and quality of particular pieces of research (including my own) but this can be a way of deepening our understanding of research in general (Garratt and Hodkinson, 1998: 534). Here, I assume there are many authors, stories and readers. No orthodox canons or single standards of value determine how illness stories *should* be conceived or constructed. As an autoethnographic author, I want to be thoughtful, reflexive and ethically self-aware in portraying others I want to evidence emotional reliability – my portrayals depicting the contours of the patient's sphere and the status of illness and health within that sphere. I want my autoethnographic story to be flexible, believable, in enough detail to express the

realities of everyday life and aesthetically appealing, but I want to explain what is going on with others, even if their actions and perceptions of events, risk, infirmity, well-being, and so forth differ dramatically from mine. I would like my reader to be inspired and stimulated into social action by the depiction of my life presented. One way of facilitating this sort of connection is to be clear about the type and scope of influence of the medical authority to which my illness narrative responds.

Autoethnographies augment empathy on multiple levels including interactions between author and participants as well as reader and story (see Bochner and Ellis, 2002). In a health and illness context, they present particular embodied events with people in time and their social shaping and how these events can be seen as emblematic of wider cultural meanings and social trends. Because of its empathic form, autoethnography provides a tool to fashion a needed 'non-dualistic ontology of the mindful body in which emotions play a central role in the human experience and cultural scripts of health, sickness, disability and death' (Williams and Bendelow, 1996: 47). In medical sociology, autoethnographies may allow both reader and author to enter into various textual strati and phases of illness understandings concerning what illness is and does to me as well as what making meaning of it involves. Do I dare feel with my story to contemplate risk, stigma and suffering alongside control, acceptance and victory? In my own life with sickness, do I interrogate myself as 'witness and doer' (Chawla, 2003)? Do I consider how the various people I encounter come to treat me in the way they do? What constrains them? What allows them to feel empowered as patients, physicians, nurses, friends...? As Berger (2001: 514) suggests, 'Am I willing to include details that might reflect badly on me, that might show me as an intransigent, nasty patient as well as an unattractive or stubborn person?' Similar to Frank (1995), Ellis's (2000: 273) optimal concern is, 'I want to think and feel with my story'. While thinking and feeling with my illness story may be a novel challenge, autoethnography can help me to achieve this aim, as you the reader will hopefully see.

METHODS: REFLECTIONS ON MY 'HEALTHY', ONCE 'SICK' BODY

I draw upon data and analyses from diaries over two years when I suffered from hyperthyroidism. These include records of key events with times, places and people as well as feelings, emotions and bodily states (e.g. pulse rates, blood pressure and weight) and relevant articles, letters and blood tests. I study my diaries and write down key events in sequential order. I remember and process them through me as the now 'healthy', once 'sick' body. Reading, remembering, writing and processing 'data' brings me emotional pain, as I move in and out of sad experiences. I recall exchanges with

'significant others'. I am aware that I interpret past events from my current position. It's impossible to get it entirely right or represent these 'significant others' completely (Pyett, 2003). I recall Ley and Spellman's (1968) classic, demonstrating that patients' information recall in communications with doctors is limited. I reassure myself, 'I won't have perfect recall' and I remember, 'Evoke in your readers a feeling that your experience is described as lifelike, believable and possible' (Ellis, 1999: 674). My story is about the past, constructed in the present. I face up to specific biographical events, placing me in shifting relations of power with myself on the healing trajectory and others, providing different levels of care. I employ the method of autoethnography to make sense of my illness.

I use emotional recall in which I imagine being back in these experiences emotionally and physically (Ellis, 1999: 675). Emotional recall is a part of sociological introspection, a process achieved in dialogue with the self and represented in narratives (Ellis, 1991). It feels healing. Like Ellis (1991: 32) I study my experiences not 'as an internal state but an emotional process which I recognize internally and construct externally'. This is linked with my emotions and instinctive reactions to others in specific places and interactions. Emotion work can be a way of reaffirming one's identity and managing the disruption of illness to one's biography (Exley and Letherby, 2001). I construct scenes and dialogue from partial images in my diaries. I analyse them according to what each story says. I place them in a time line. I know my story is not totally precise and some events may be out of place. I am fascinated as to what I will find and how I will feel. I have events before me as well as situated settings, sites and conversations. I notice in writing and analysing a sense of triumph prevails; I have survived death. I beat this punishing illness. I want to explore the multiple subject positions experienced through my transformed body. Yes, I am healthy now but a different 'healthy Betsy' than before I became ill. The cartography of acute illness has brought me 'health' but via a circuitous route, one that included choices to take an alternative path, leave my General Practitioner (GP) and from the viewpoint of biomedicine, put myself at risk of more physical harm or even death. Perhaps, in focusing on what my story is saying, I misrepresent what is going on for significant others. I found some of their behaviour difficult. While my story is no less true than theirs, it is hopefully more intimately engaged, giving access to unwelcome and painful processes and critical insights into biomedical conventions. I found comfort from my suffering in a way that differs from a biomedical way of expressing it (Ahlberg and Gibson, 2003). I want to be ethically accountable in terms of how I portray others. My data source is personal diaries. There are no research participants according to the remit of Research Ethics Committees (Beyleveld *et al.*, 2002) nor anyone identified as a conventional respondent from whom gaining informed consent is required (Crow *et al.*, 2004). However, I inform all significant others

with one exception³ of my account in writing or verbally. I protect their anonymity. Names of people and places are changed. With three significant others, I discuss what I do. They give support. One agrees to read the first draft and finds it 'riveting'. Talking to others involved in my story is important. I gain self-assurance, while they gain important information and the opportunity to consider that understanding a middle-aged female patient's experience of an acute illness may improve their own practice.

While I did not seek ethical approval, some could argue that I should have. This is debatable and there is no space to discuss ethics in detail here. Briefly, if I see ethical accountability in terms of personal integrity, this may be problematic, revealing my attempt to fit into an 'empty ethics' model (Corrigan, 2003). From the viewpoint of non-normalizing ethics based on personal choice rather than social and legal imperatives (O'Leary, 2002: 7), I am an appropriate ethical authority, granting permission to write my story because it carries the weight of historical and moral necessity – I survive to tell it. I am responsible for my own illness story – no one else. Some significant others in my story know this and may be troubled. Originally, I did not set out to tell my story. It is my choice to narrate events and feelings. Frank (1991: 19) suggests that accountability and ethical 'responsibility begin and end' with the narrator, framed by 'an ethics of the body' where observations and witness commence, sustaining corporeal wholeness. Here, one's position, in contrast to a code-based morality reflected in biomedicine, begins from an 'aesthetics of existence', the heart and indeed art of ethics (Foucault, 1984).

MY ILLNESS STORY⁴

(mid February 2001) 'Why am I falling on the stairs? I have terrible diarrhoea ... Maybe I am menopausal. I get palpitations ...' I am scared. I am becoming unwell. Two weeks later I visit Dr Walsh, my NHS⁵ GP. 'Dr Walsh, I have been having bad diarrhoea for the past two weeks', I say softly. 'Could it have been something you ate?' she asks ... 'Well, perhaps', I say. 'Sometimes, food poisoning takes a while to get over. It's probably that', she says. Worried, I add, 'I get horrible hot flashes and palpitations too.' My right hand shakes violently. I sit on it hoping that Dr Walsh doesn't see. 'Well, that could be menopause. Would you like something for it?', she asks. 'No, thank you', I reply.

For the next three weeks I am in Helsinki. My diarrhoea subsides for the first few days and comes back. I walk after presenting a university seminar. I think, 'I am so breathless all the time. I didn't feel nervous when I gave my paper, but my hands shook. Strange ... I wish this diarrhoea hadn't come back. The hot flashes and palpitations are awful. I hate this menopause feeling.'

Three weeks later, I sit with Dr Walsh, 'I was away since I saw you. Most of that time, I had diarrhoea, but not for the past two days.' 'Have you been stressed?', she asks. 'Not particularly.' I pause. 'Yes, I am writing two books', I say. 'It could be psychosomatic – you could have the beginnings of irritable bowel syndrome', she says. 'Oh, I know that. My mother suffered from it for years', I say. 'Ah here it is', she says as she hands me a small cylindrical container. 'I want to take a stool sample to be sure you don't have an infection. Bring this back tomorrow. We'll get it analysed. Ring up for the results. If it continues, we'll get a blood test for you. Then make an appointment with the nurse.' 'Thanks, doctor', I say. Four days later I ring the surgery. 'Your stools are all clear', the receptionist responds ... 'Thank you', I say ... I think to myself, 'What a relief!' Two weeks pass ...

'Dr Walsh said to get a blood test if my diarrhoea continues. It has, but this week it's not bad', I say, closing the door to the nurse's room. A short, young woman in a blue uniform says, 'Well, you don't need a blood test.' 'I'm not sure. This has been going on for some time', I say, surprised at her abruptness. 'Let me speak to the doctor.' I wait feeling nervous. She returns. 'Dr Walsh says that you don't need the blood test.' 'OK', I say in a resigned voice.

Over the next six weeks, I lose weight and eat a lot. I should be relaxed because my projects are finished but I'm nervous all the time. My partner begins to notice. 'It feels like a river is running through my body', I tell her. I go for a blood test. There is something wrong. 'I have come for a blood test. My diarrhoea has not stopped', I say to the nurse the next day. 'For how long has this been going on?' she asks. 'A few months ... I came five weeks ago. Dr Walsh said I didn't need a blood test. Don't you remember?', I ask feeling frustrated. 'OK I'll get the syringe', she says. The next day I receive a phone call from the receptionist telling me to see Dr Walsh. I sit in front of Dr Walsh who seems rather upbeat when she fetches me from the waiting room. I say, 'You wanted to see me about'. Before I finish my sentence, she says, 'Yes, your thyroid has packed in.' 'What does that mean?' I say feeling confused. She continues in a reassuring voice, 'Your thyroid is overactive. Your antibodies are destroying it. You are the second person today that has this diagnosis. The other is my father-in-law.' Sensing that she is in her element, I think, 'She's being friendly but I don't want to share my consultation with her father-in-law.' She continues, 'There are three options. We can cut the thyroid out. You can swallow radioactive iodine which kills it. You can take anti-thyroid tablets. I usually recommend the latter, carbimazole, which is perfectly harmless. What do you want?' I am confused; I don't want to become chronically ill. I say, 'Well, I don't want surgery. The radioactive iodine doesn't sound good. My mother has had cancer and I am afraid if I am

susceptible.’ ‘There is no connection with cancer. Radioactive iodine is perfectly safe’, she retorts. I say, laughing nervously, ‘I am not sure. I’ll take the pills.’ The prescription is handed to me as she moves her chair towards me. ‘I wonder when she wrote this’, I think. She takes my wrist, ‘Your pulse is 126, a little high⁶ but expected. Take the pills. Come in a month’s time for a blood test and we’ll review your dosage.’

Thirty minutes later I phone my partner about my visit with Dr Walsh. I am worried and remember that my mother had the same condition. I want to phone an alternative physician who my osteopath recommended once when I had hot flashes. My partner says reassuringly, ‘That sounds like a good idea if you are afraid.’ And I was. Five minutes later I ring Dr Fish and say I received a diagnosis of overactive thyroid. I am afraid to take the pills my GP prescribed. I say that I would like to explore the possibility of taking alternative medicine with her as soon as possible. Luckily, she has a time later in the day. Six hours pass . . .

I am at Dr Fish’s private clinic. A stately woman enters, her right arm extended to take my hand. She guides me to her office. I feel her warmth immediately. ‘Nice to meet you Professor Ettorre. Describe how you are feeling. I am sure we can sort something out.’ ‘Not well. I feel as if a river is running through my body. I have terrible palpitations and diarrhoea. I am irritable and can’t sleep’, I respond. She turns toward me and says, ‘Tell me if you have had any poisoning recently.’ ‘No, I don’t think so’, I say with interest. In our conversation, she says that poisoning can cause thyrotoxicosis and if a patient’s pulse goes too high, it can be life-threatening, causing cardiac arrest. I shudder with fear and speak about my diarrhoea, my other symptoms and my visit to my GP. She takes my pulse which is 120, says it is usual for thyrotoxicosis but a normal pulse is around 60–70. She speaks about her patient who had the same condition and got better by taking a herbal remedy. She says that thyroid sufferers often feel as if they have no space to speak and asks if I feel that. Immediately I feel a visceral sense of loss. Vulnerable, I start crying. Tears run down my cheeks. I respond, ‘Yes, in a way.’ I speak about recent grieving and say, ‘If a normal pulse is 60–70, I am sure I have not had one for some time.’ She looks quietly then says, ‘I am going to prescribe you an herbal remedy for thyrotoxicosis. You have to slow down. Can you do that?’ ‘Yes, I am off on holiday in two days’, I say. She asks to see me in three weeks. I say that is impossible because I will be in the USA to attend some conferences. Looking shocked she says, ‘Well, that isn’t a rest. You must slow down. I’d like your GP’s name. Also, ring me while you are away to tell me how you are doing. I’ll see you soon after you get back. Find out your blood test results. Your GP will give them to you.’ We agree that I’ll ring her from holiday.

While away, I take my pulse everyday. The range is from 81 to 124. I ring Dr Fish three times to say I am resting and feeling better. In

Anaheim, California, I present papers at the Annual Conferences of the Society for the Study of Social Problems and American Sociological Association and I attend Sociologists for Women in Society. Besides giving papers, I rest and swim in the hotel swimming pool to relieve my symptoms. Colleagues walk past and greet me. I feel ashamed because they may think I am lazy. On my return, I have a blood test taken by Dr Walsh's nurse. She gives me the results of my first blood test. I say nothing about Dr Fish who I meet the same day and gives my blood test results⁷ which are for 'free thyroxine',⁸ 71.2 and 'TSH',⁹ 0.01. Dr. Fish says, 'Remember herbal medication works slowly. If you take carbimazole, it's like taking a sledgehammer to your thyroid. Herbal medication works gradually but you need to slow down. Tell your GP that you taking the herbal medicine. It is in your best interest to do that because if anything happens she is legally responsible. It is only fair that she knows.' I am anxious but say, 'OK, I'll do that.' Dr Fish notices my anxiety, 'You are a professor. I am sure you can talk with her'. I don't feel reassured but say, 'Yes, I am sure it will be fine'. We arrange another consultation in three weeks time. When alone, I think, 'I'm an educated competent woman who's afraid of her GP – a first for me. When I read that extreme nervousness and jangled emotions trouble 99% of Grave's sufferers (Gomez, 1994: 48), I begin to understand.

A week later, I see Dr Walsh. I am anxious. She doesn't ask about carbimazole. I can't tell her about the herbal medication – jangled emotions! I am feeling desperate. Looking at her notes, 'We have the results of your blood test. Your free thyroxine is 55 ... TSH the same. You don't need to see me any more. Take the medication and go to the nurse for blood tests and we'll monitor you that way.' I think, 'How different her consultations are from Dr Fish's'. I say, 'Thank you doctor.' The next day I meet with my Dean. I say I am being treated for thyrotoxicosis and need less work. He agrees, is sympathetic and says his wife had the same condition. I am grateful for his understanding.

Five days later, I see Dr Fish and say my blood values are down. She says this is good news. She says I need to pace myself because the herbal medication works slowly. She wants to know if I told Dr Walsh. Reluctantly, I say no because I was too frightened. Dr Fish volunteers to tell her but I say I'll do it. Because of my jangled emotions, I take carbimazole for a few days. I don't want to lie. I am sitting uncomfortably with Dr Walsh's nurse a week later and say, 'I've come for my blood test.' She gets the syringe and takes blood from my arm. As she does, I say bracing myself, 'I am improving, I was taking herbal medication but now I am taking the carbimazole.' She finishes and looks at me, 'Did I hear right? Why do that? Let me hear your heart.' She puts the stethoscope to my chest. 'Your pulse is racing. I need to speak to Dr Walsh.' She panics, rushing out of the room. I feel a bad patient. Five minutes later, she stands in front of me, 'Dr Walsh is not happy about

the herbal medication.' 'But, I have improved, I . . .', I begin. She cuts in with a scolding voice, 'It doesn't matter. You must get an ECT. You have palpitations which need to get seen to. You need beta blockers. You'll get a letter. Promise you'll go this week.' Feeling demoralized, I say, 'Yes, I suppose' but I think, 'Not on your life. I am never stepping foot here again.' In my parked car, I ring Dr Fish. I ask to come to see her soon because I want her help to find a sympathetic GP. When we meet in two days' time she tells me that what is happening is stressful. She wants my pulse down and warns that I could have major health problems, if it doesn't. I tell her how I took the carbimazole temporarily so as not to lie. She reassures me by saying that of course I can take it, if I choose to and she asks how it feels. I say I stopped and that for the first few days, it was OK. But soon after I got terrible headaches, my pulse and my blood pressure shot up and the palpitations were violent. She suggests that she take my next blood test and she'll sort me out for a sympathetic GP. She has a book of registered alternative physicians and gives me a list of names. That same evening I ring the names on the list. One doctor is unable to help because I am outside of his catchment area, but he gives me the phone number of Dr Edwards, a trained homeopath as well as GP in my area. The next day I ring Dr Edwards's surgery, find out the address and go to register. I make an appointment to see him after he returns from his holiday. Sometimes, I feel like I want to die. A month passes . . .

My blood test from Dr Fish shows my values going down. I see Dr Edwards and tell him about my overactive thyroid, my herbal medication from Dr Fish and leaving Dr Walsh. Dr Edwards is a man whose weathered, open face I am immediately drawn to. Looking at me directly, he says in a soft voice, 'To be honest, carbimazole is not pleasant and can have dangerous side-effects. Unfortunately, it's the most common drug used for overactive thyroid. If a patient does not want to take a drug, she shouldn't. It's your body, not mine. You shouldn't feel forced to take a drug. But, one thing we were told is that homeopathic medicine doesn't work for thyroid conditions.' I breathe a sigh of relief. I feel comfortable with this man. 'I am not using a homeopathic remedy, only herbal medication', I say. He begins to write and looks up asking, 'Are your blood values improving?' 'Yes. I feel better than when I was first diagnosed. He continues, 'Did you ever take carbimazole?' 'Yes, for a few days but I felt sick. I felt as if my eyes were popping out', I say. Our conversation continues in a calm manner. He suggests that I continue my herbal medication, have my blood tests with his phlebotomist and copy my results to Dr Fish. He agrees to monitor my progress and asks me to consider sick leave and he'll sign me on.¹⁰ He asks to see me in a few weeks and thanks me for coming. I leave feeling elated because he is empathetic.

A month later I go to his phlebotomist, a young nurse with a professional manner. She explains what she will do and shares that she has an

underactive thyroid. After she takes my blood, she asks me to ring her for my results. When I leave, I notice how calm and satisfied I feel. A week later, I receive my results – an improvement. My free thyroxine is 24.9, but the TSH is the same. I see Dr Fish and tell her the news and about meeting Dr Edwards. She notices my right eye¹¹ is slightly bulging, a classic sign of overactive thyroid and asks if I want an eye specialist. I say I am trying to avoid doctors. She laughs and says, ‘You must be relieved now that you have Dr Edwards. Just going to a doctor can cause stress and this is what we want to avoid.’ Two months pass . . .

I go on a Christmas trip to Lapland with friends and feel well enough to ski. On my return, I have a blood test and see Dr Edwards. He tells me that I am not yet normal. My free thyroxine levels go up while the TSH remains the same. I say that I’d like to take sick leave. He agrees saying, ‘That is fine. I’ll sign you on.’ While on sick leave I go to my Osteopath who suggests that I do yoga because I have a stiff shoulder.¹² I phone a yoga teacher, tell her that I have an overactive thyroid and think yoga would help. She tells me that her sister had the same problem and yoga helped. She asks me to come this evening and I agree. Immediately after class, I notice my pulse goes down. I want to do everything I can to get better. Dr Fish suggests that I have my amalgam fillings removed. I have them replaced,¹³ taking six months. I eat organic food, do yoga, drink little alcohol, take my pulse daily and ‘pace’ myself. I renew an old activity – ‘doing nothing’. This involves me sitting and doing nothing. That is how I used to calm myself when I was younger. I find ‘doing nothing’ healing. I sit back and think about my life. It is a ‘reflexive’ luxury for me. I talk with colleagues about how all of us in the academy need to slow down in our stress-filled lives. Almost a year passes . . .

I feel much better. The palpitations stop. My pulse is down. In January, I go for a blood test. By this time, I agree that I ring the phlebotomist directly for my results. In mid-February, I am abroad at a meeting and during a short break, I ring the phlebotomist. After I hear her voice I say, ‘Hi, it’s me Elizabeth. Do you have my results?’ She responds quickly, saying, ‘Yes, let me find them.’ There is a pause and shuffling of paper. ‘OK Elizabeth, here they are – 15.2 your free thyroxine and 0.46 your TSH. They are normal.’ ‘That is great’, I say with joy. ‘Do you know this is the first time my TSH is normal since I started having my blood tests almost 18 months ago?’ ‘No, Elizabeth, I didn’t. That is very nice to hear’, she responds excitedly. ‘Congratulations’, she adds. I feel full of delight. ‘OK, I’ll see you at my next blood test and thanks’, I say, before I hang up.

Eight days later I am with Dr Fish who wears a lovely floral dress with a matching scarf. The sun is shining through the window onto her desk. I am smiling. ‘Good news, Dr Fish, I am finally normal’, I say. She smiles too. ‘Well done. I knew you would do it. All of your discipline has paid

off. 'I must tell you', she says as she looks over my notes. There is a long pause. 'I am just looking at your notes from our first consultation.' She looks up, 'When you first came to see me, you had all the symptoms of acute thyrotoxicosis. I was very worried about you. You could have easily gone into what we call 'thyroid storm',¹⁴ had a cardiac arrest or even died. I just kept my fingers crossed that you would pace yourself so you would go slower. I am very pleased for you ... 'I smile and feel deep joy ...

'GONNA TAKE A SENTIMENTAL (ILLNESS) JOURNEY'

With the backdrop of sorrow, my autoethnography details physiological changes that occur, embodied choices I make and participatory frameworks in which these are set. But when I am ill, there is work to be done by me and others. The entirety of work organised over the course of an illness is incalculable. Making embodied judgements is hard work for the patient as is being shaped as the technician of practical and technical knowledge for the doctor. In this context, Strauss *et al.* (1982: 254), define instrumental work or more accurately, 'sentimental work as any work where the object being worked on is alive and sentient'. While they translate this into the treatment of the chronically ill in 'technologized hospitals', their ideas are useful in a wider clinical context and specifically, in providing a context for my autoethnography. I am slightly cautious of the functionality of the Parsonian framework they employ (ie, instrumental and expressive labour); their rather one-sided, limited definition of this kind of work (eg, the focus is on medical professionals not the 'work done by the patients'¹⁵) and their apparent prioritization of chronic over acute illness. Nevertheless, their analyses allows us to move across and beyond established medical categories, corporeal boundaries, structured exchanges within the clinic and various intensities of experience which shape as well as resist categorization. Most importantly, sentimental work suggests the problematization of illness and desire for health as a powerful force that needs to be morally regulated.

For these writers, the sources of sentimental work include a perspective on medical personnel's trajectory work, both expressive and instrumental. Highlighting different modes of disciplinary regulation, sentimental work is spatialized from the ever present possibility of clinical danger, is commonly done by strangers to the patient, takes priority over other considerations, such as getting to know the patient, and has a temporal expanse which may last for days or even weeks. On the one hand, these sources may be a bit outdated, as evidenced by the work of Zussman (1992), Chambliss (1996), Timmermans and Berg (2003) and Foucault (1973). Nevertheless, Strauss and his colleague's identification of the diverse types of sentimental work suggest a panoply of disciplinary procedures, circulating between

localized individuals in the clinic. That interactional and moral rules, trust work, composure work, biographical work, identity work, awareness context work and rectification work are dramaturgically significant in clinical contexts is, in my view, theoretically compelling and remains topical.

In relation to my autoethnography, embodied self-assurance in the midst of disease is established in *trust work* which begins between Dr Walsh and myself, although she is a stranger to me and I to her. I sense intuitively there is something wrong with my body. We also engage in *identity work* because I am menopausal. I resist the notion of menopause as making me feel deficient (Woods, 1999; Murtagh and Hepworth, 2003). That is how I feel and I sense Dr Walsh knows it. I am not a 'hysterical', menopausal woman as portrayed within traditional medical discourse (Caplan, 2001). While menopause is a status passage, medicalizing this transition allows its social context to be ignored (Ballard *et al.*, 2001). We both resist the urge, although HRT is most kindly offered. Thus, Dr Walsh responds by doing what she is best at – finding the 'basis', doing diagnosis and making use of her medical gaze. On the other hand, an attempt at restoration of trust or *rectification work* appears when the practice nurse 'picks up the pieces' (Strauss *et al.*, 1982: 265) when she learns of my resistance to medical authority. She panics. I am afraid by the efforts of helpers around me to shape my life according to categories denoting health and pathology (Urla and Terry, 1995). 'Nurse' attempts to harness my body into an object of a new biomedical discourse, cardiology. I challenge her brusqueness and further pathologization: the treatments and procedures provided by her, Dr Walsh and the yet unknown cardiologist.

Glaser and Strauss (1964) coined the term 'awareness contexts' when looking at the sorts of interactional difficulties surrounding the dying in hospital. Identifying a range of awareness contexts, they looked at how social order was maintained in the face of the disruptive threat, death, and how the spatialized regime of the hospital accommodated the unintended consequences of impending neurological occurrences. When I choose alternative therapy, it becomes a negotiating process between me and caring doctors (Burnell, 2001), Dr Fish and Dr Edwards. We work on establishing *open awareness contexts*. I know what is happening to me and my body and the potential risks of my condition. The doctors know that I know. This knowledge leads me to a heightened attentiveness of my desire for health as well as a profound sense of losing my voice which Dr Fish points out is part of 'doing thyrotoxicosis'.

My 'recovering' body learns to express itself again as calmness and equanimity are restored in *composure work* when compassionate words by Dr Edwards are uttered; I find mercy in myself doing yoga; Dr Walsh smiles; Dr Fish finds a low pulse or the phlebotomist holds my hand. We do *biographical work* when the phlebotomist shares her own embodied

secret: she has an underactive thyroid. My Dean and I do similar work when he tells me his wife shares my condition. Dr Walsh does when she mentions her father-in-law. Dr Walsh interrogates me for examples of stress, while Dr Fish links thyroid disorders with lack of emotional space. I exercise class privilege by contacting Dr Fish. All are intricate pieces of a complex illness story.

I am recognized and recognize myself as ill in these encounters, as we engage in *interactional work* and *setting moral rules*. I am not yet diagnosed 'officially' with an overactive thyroid by Dr Walsh, although she takes up her instrumental role competently. But, my own transgressive role breaches the boundaries of our medical interaction. This estrangement may imply that Dr Walsh is not compassionate, a quality apparently evident for both Drs Fish and Edwards. Whether or not this is true, a doctor's behaviour is capable of change and communication patterns between doctors and patients have been known to transform from strictly medical encounters (which Dr Walsh and I share) to those in which engagement in a mutual life world is possible (Barry *et al.*, 2001). Indeed, health care relationships can be spaces where the expertise of both patients and health professionals are pooled to arrive at mutually agreed goals (Bissell *et al.*, 2003). However, when the rules and boundaries of medical interactions are breached, *rectification work* helps stem resentments and feelings of hurt. I use the counterpower strategy of 'exiting' by changing my health care provider (Asbring and Narvanen, 2004), while perhaps in Dr Walsh's eyes, I exercise non-compliance (Pollock, 2001) and am the traditional problem patient (Lorber, 1975).

CONCLUSION

The use of autoethnographic data chronicles my illness experience from a 'difficult' to an empowered patient. My wounded, misunderstood body was becoming not only a healthier body but also more reflexive, 'capable of ruminating, deliberating, cogitating, studying and thinking carefully' (Martin, 2003: 356). I learned that my self-identity, emotions and experiences were shaped by biomedical experts' risk calculations about my ageing body. My menopausal body at risk took on a contingent character and was emblematic of middle-aged women whose future lives were punctuated by troubling symptoms. While the problems I encountered were socially constructed and political as well as personal and biological, I have attempted to bring corporeality into the debate about women's bodies without biological reductionism. For example, I contend that experiences of thyrotoxicosis as an autoimmune disease be revisioned from a perspective which challenges current biomedical ideas about the negative

workings of women's immunological system (Martin, 1999) and the indispensability of allopathic medicine and traditional medical authority. This sort of perspective has methodological implications. For instance, Kuhlman and Babitsch (2002: 440) contend that feminist theorists must take empirical data gathered by women's health research and the multi-faceted dimensions of bodily perceptions into account when formulating ideas. The empirical data detail my physiological changes alongside my embodied choices with the backdrop of the loss of my healthy body. Choosing alternative therapy led to a heightened awareness of the importance of 'gendered illness matters' (Chrisler, 2001) and eventually, the beginning of healing. My experience of thyrotoxicosis, revisioned from a feminist perspective, illustrates the importance of sentimental work in illness encounters. The profound sense of losing my voice through my jangled emotions was intimately linked with 'my disease'. This is not new in medicine. As 'a crying' body learns to express itself again, the thyroid gland becomes implicated in this intensely emotional, embodied experience (see Lutz, 1999: 91). In the face of medicine, I suffered 'demoralization' and found that a healing generosity was lacking (Frank, 2004).

I began with the assumption that being reflexive about one's illnesses, especially through autoethnography, can be a useful learning tool for medical professionals and patients alike. I desired to become a communicative body (Frank, 1995), offering generous greetings to other ill bodies with similar experiences. Whether or not I have achieved this level of generosity, I have through autoethnography 'given voice to my body' (Sparkes, 2003b: 64), experienced a connectedness to others (Richardson, 2001) and bore witness to how embodied identifications with others are able to induce dialogical exchanges. In learning from personal sickness narratives, let's challenge outdated medical practices, based on gendered stereotypes of ageing, sick, female bodies. Being reflexive through autoethnography is one way of mounting this challenge.

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NOTES

1 Also known as Grave's disease, hyperthyroidism or overactive thyroid, thyrotoxicosis is an autoimmune disorder which occurs when one's own antibodies attack and begin to destroy the thyroid gland.

2 These were daily palpitations, joint pains, general muscle weakness, floppiness, falling, sleeplessness, weight loss, tremor, 'gritty' eyes, vitiligo or discolouration of the skin on the neck, diarrhoea, irritability, high pulse, damp skin, brittle nails, dull hair, hair loss, swollen neck and difficulty in swallowing.

3 I could not find a current address.

4 The following texts are data based on extractions from my diaries.

5 NHS = National Health Service, the State-funded health service.

6 This is my resting pulse. I am twice the normal rate.

7 Blood values vary between laboratories. At mine, the normal range for free thyroxine is 2.8 – 23.1 and for TSH, 0.35 – 5.5. (I am 3 times the normal value.)

8 This is the tiny but significant part of the main thyroid hormone. Its level in the blood is useful in assessing whether the thyroid is functioning properly (Gomez, 1994: 119).

9 TSH or thyroid stimulating hormone is produced in the pituitary gland and directs the thyroid to produce hormones. TSH goes up when the thyroid isn't providing enough ... and down when there is a surplus (Gomez, 1994: 119).

10 In Britain, in order to get statutory sick pay, a NHS GP needs to 'sign you off work'.

11 This was noticeable by my partner, friends and colleagues from September 2001 until October 2002. The bulging coincided with my taking the anti-thyroid drug, carbimazole.

12 'A frozen shoulder' is common in thyrotoxicosis. This is inflammation of the covering of the shoulder joint (Gomez, 1994: 97).

13 Before taking out my fillings, the dentist tests the electric charges triggered by them and they are abnormally high.

14 This is an out of control thyroid. It is viewed as life threatening when it occurs and requires 'instant hospitalization and energetic anti-thyroid measures' (Gomez, 1994: 63).

15 See Werner and Malterud (2003) for a discussion of this type of work.

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