

The Language of Cancer: *exploring resilience, responsibility role and rebellion through personal reflection.*

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## Context

In February 2019 I found myself undergoing tests for gallstones, the latest of which had been a CT scan. Whilst awaiting the results my GP rang me up at 7pm on a Friday evening. Doctors don't normally ring at this time at the start of the weekend, so I guessed the news wasn't going to be good. Perhaps, I thought, it was my gall bladder too, or I needed it taken out quickly. Instead she gave me a run down of what was good. The details of my gall bladder, although needing to be removed, were rattled over far too quickly for it to be the cause of concern. There was a point she was getting to, and the gall bladder wasn't it. *'But they've found something else,'* she began, *'a three-centimetre lesion in your right lung'*. These last few words were expressed slowly and deliberately.

A.

Three-centimetre.

Lesion.

In.

Your.

Right.

Lung.

I listened in something like dazed disbelief. *'I'm making a referral this evening and you'll be contacted in the next two weeks for an appointment'*. She was telling me that she was taking this seriously and, by implication, that I should too. Questions followed and they were patiently answered, and the offer of being available to talk to at the end of the phone was given and taken up the very next week.

Three months later I am not at the end of the tunnel. Not just yet. The truth is they don't know whether the '*lesion*' is cancer or not. Fortunately, they are not so worried and I no longer have phone calls on a Friday evening. Instead I have 6 monthly scans to check the growth of the tumour to look forward to.

## Blogs

The following are extracts from some of the blogs I made, that helped me to express the confusion, anger and uncertainty I was experiencing, and continue to experience to this day.

Through reading and re-reading them I now realise that I was grappling with ideas associated with the power of language and our perceived roles as social actors, and our agency both viz a viz disease and as patients. For me, language is closely associated with discourse – with big ideas about the organisation of society, how services are organised and delivered, and our role as patients, tax-payers and members of wider society. Before I unpick those, it is worth going back to the blogs. For ease of reading I have merged and edited two specific blogs in order to provide context and the development of the story I wanted to tell.

*So, here is the rub. I have cancer. Writing those 3 words seems strange and, in typing them, I wonder if I should use a different font, another size or coloured each letter differently like something you see on CBeebies. Instead, deliberately or not, I have opted to be understated, muted so that there is a chance you might have missed that small three-word sentence at the top of the paragraph. (I have visions of some of you going back to the top and reading this again, worried that you've overlooked something).*

*Yeah, by some strange quirk of fate, and less than a year after nursing my Dad through his own version of the disease it is my turn. Fate's finger doesn't seem so fickle from where I am sitting. Instead it is jabbing me just where it hurts with a bony sharp digit shouting 'Your turn, Bastard!'*

*It hurts. To be brief, fate has a sense of humour. Eight years ago I had an earlier cancer scare, but what was first thought to be mesothelioma turned out to be an undigested piece of food that did, what my mother always said it would do if I gobbled up my food too quickly, and go down the wrong way. The lower lobe of my left lung ended up rotting. It had to be removed. At the time both lungs were scanned and, because they were focusing on the 'poorly' lung, the doctors missed some action on the right-hand side. Scroll forward eight years later and a CT scan picks up a 3 cm 'lesion on the right lung' which, after a rapid but grand tour of the NHS' various screening facilities, turns out to be cancerous.*

*Now, having cancer it seems isn't a leveller. I can't quite look all other people living with, or dying from, cancer in the eye, like the Queen Mother felt able to do during the Blitz. Instead, it seems that people with cancer end up like the John Cleese/ Two Ronnies sketch from That was the week, that was, or TW3 as it was known. (If you're not old enough it was a satirical sketch show from the 60's). The tall upper class 'nob' played by a bowler-hatted John Cleese is, in my example, the terminally ill person, who can look down on the others for having a lower grade/ less serious cancer. I know my place. I am the cloth-capped Ronnie Corbett- type patient, looking up at the other more serious ones, far more ill (or is that ill-er?) than I am.*

*Although I have a lung cancer, mine is a lazy, possibly 'indolent' cancer that has been growing for years, if not decades. In fact, in eight years it has managed something like 4mm. Hardly Usain Bolt. It is the lazy kind of cancer that would be denied Universal Credit by an ASOS assessor. The Andy Capp of cancers, with an extra-large fag or reefer hanging from his lip.*

*So, having been diagnosed I am in a no man's land that many people find themselves in, not knowing what to do and waiting for more tests. My left 'poorly' lung is due a wash as it has some sort of raging infection, and the right*

*hand one is due a bronchoscopy. It's one way of getting over familiar with my tumour. Then the fun begins, we either leave it, zap it with Bikini Atoll scale radiation, or take a pair of scissors to it. Maybe a mixture of all three over a period of time.*

*As a consolation prize I now enter the world of being both an academic and a service user. That rarefied position, that gives the academic researcher extra kudos. It is here that I achieve a John Cleese bowler-hatted status. I ain't getting off this pedestal fast! In fact, I am not going anywhere. I am not going to be defined by this disease in a 'battling with cancer' label kind of way. I'm not being 'brave'. No pink ribbons adorning my social media photo for me, and even if I could I am not going to run a marathon or ask people to do it on my behalf. I tend to subscribe to the Christopher Hitchens' 'perverted pregnancy' approach to cancer. If anything it's battling me, the lazy bastard. So rather than using notions of battles and fights, I am going to adopt a fagless Andy Capp pose, and sit here with my pint, and catch it when it dares to show its face. I'm going nowhere until I do.*

*One of the things that I'm finding difficult, at the moment, is how I actually express the sense of having cancer. Whilst I am prepared to acknowledge that it might be different for others (after all were all supposed to be different), much of the language I come across rankles with me. Like Cinderella's slipper it either doesn't fit or fully explain my personal situation, and it stands directly opposite to my way of viewing the world and viewing myself viz a viz the tumour in my lung. If you read much of the literature put out by charities and social media it would be easy to assume that I am 'brave', 'battling', 'standing-up' to this illness, on a spectrum where I am part 'victim', and yet part 'hero', simply for having a genetic mutation. I am the unwilling Frodo Baggins on some epic journey to rid myself of my 'precious' Nigel. (Yes, my tumour is called Nigel). It becomes something I have to 'beat'. The language of violence, and mainly an 'active' form of violence, surrounds the mainstream manner in which*

*we encounter this concept. As such, it is not surprising. What cancer does is subject those who have it with a form of violence both directly, through what the illness does or can do, and indirectly through the treatment. Yet the language still hangs on me in an ill-fitting overcoat.*

*Whilst I don't doubt that the many people living with this illness in its many different forms can be seen as heroic, I'm not. I don't plan to be. I am both more, and less, than this illness. I steadfastly stand against being framed by it, and whilst that may sound like some form of 'denial' frankly, my dear, I don't give the proverbial. Whilst I might, quite literally, have to 'stand up' for haemorrhoids, would I be considered 'brave' or 'battling' them, if I had them. Would I be a 'hero' for overcoming them through surgical treatment or a diet of soft veg? I doubt it.*

*The language that surrounds cancer is an easy and, dare I say, lazy language. Made more so by the cancer 'industry' that has grown up around it, where people are encouraged to sit in baths of cold baked beans, run marathons, or endure another indignity for cash. Here it isn't our birth-right that demands government invest the money on research on our behalf, but instead we become dependent on the efforts of a group of schoolchildren selling yet more biscuits and doing bigger, better and longer sponsored silences.*

*We are not so much the victims of a harsh disease than of a neo-liberal approach to research and treatment, that suggests that you're on your own, apart from a sponsored phone-line and a health service close to collapse.*

*It is in the middle of this landscape that people, and their loved ones, find themselves in when having been diagnosed with cancer. Nothing fits. Medical language is, sometimes quite literally, Latin and it confuses and obfuscates. Doctors and nurses, rather than saying you're number is up, talk instead of spending quality time with family. It is here that our illiteracy surrounding*

*cancer finds expression on social media with teddy bear and rainbow filled memes that talk to everyone in general, and no-one in particular. What has a teddy bear or a unicorn got to do with cancer? Well, they're are simply the visual manifestation of the silent and silenced open-mouthed public, who can't quite get the right words to come out.*

*The wrong language and a lack of anything suitable leaves us all, patients and loved ones, verbally inert. And me? I am still seeking for the language to explain how I feel, and how I am. For now it is enough to know that what is out there isn't enough.*

Resilience.

So, there it is, or was. Looking back a few months since I wrote these blogs I find myself exploring how I think my own personal experience, and the anger that it provoked in me, says something about how language helps to constrain our sense of agency, and frames both our behaviours as patients and those of the professionals. Moreover, I also think that it provides a commentary about how health services are increasingly organised, provided and not provided in a neo-liberal society. One of the first things I have turned to in order to explore the language of cancer is the notion of *resilience*. It is here that concepts associated with '*fighting*', '*battling*' and '*bravery*' are firmly embedded, and become enhanced by the idea that some crises might actually be beneficial, '*... forcing us to consider issues of ... adapting and renewal...*' (Joseph (2013), pg 3). The resulting change is considered as being simultaneously 'better for us', 'character enhancing' and a 'learning experience'. Coping, in this way, is regarded as creating strategies that set us up for other 'battles'.

One of the starting points I find myself using when trying to unpack this type of narrative is to turn to Hutcheon and Wolbring (2013) who, in exploring the relationship between resilience and disability, suggest that resilience is used to '*... describe the personal qualities, competencies, processes...*' that might lead to '*... "satisfactory" outcomes in individuals under threat...*' (Hutcheon and

Wolbring (2013)). Within the context of cancer, as opposed to disability, these 'qualities' and 'competencies', such as bravery and the notion of the ability to do battle with the disease have been defined for us, using narratives offered by wider society and utilised by cancer charities and professionals. We become battling, fundraisers where fighting off our own nausea caused by violent toxic treatments we are shaving our heads and sitting in custard to raise funds to pay for the allied care and support we need. These narratives locate us in specific circumstances as particular 'actors' with a straightjacket of set roles ignoring and side-lining our own sense of agency as individuals, and our ability or willingness to '*... self-define as resilient or not resilient*' (2013). Having cancer then demands that we must strive to become healthy and normal once more, within a context where our own '*...fortitude surmounts adversity...*' (Hutcheon and Wolbring ,2013), and where the individual becomes both '*heroic*' and '*inspirational*' (2013). As such these ideas have become '*common sense*' and '*...extraordinarily seductive...*' (Slater (2014)) as a narrative within which everyone (such as charities and a neoliberal state ) benefits

By demanding that we must become 'brave' and are to 'fight' cancer, individual patients, like me, are being handed a responsibility for their outcomes, where success, or failure, in overcoming cancer is somehow up to me. This might include responsibility to take medication, to exercise, diet, to not smoke etc, to do things that keep me 'healthy' within a wider narrative of 'self-managed care'. Outcomes have nothing to do with the fact that we are victims of differential access to care and treatment, and the vagaries of the NHS treatment purchasing regimes.

Yet if we follow a classical Gramscian approach to the links between language and power (Fairclough (2013)), we can see that this narrative justifies and excuses the withdrawal of state funds and institutions that might otherwise provide support and care for me. Here then, patients like me are regarded as

needing to develop resilience strategies that will allow us to achieve greater self- control, better flexibility and progress towards something Diener (2003) refers to as a 'Pollyanna-like state', that uncritical and unquestioning stage of self -awareness, within a world that is understood to be outside of any personal control, and therefore not worthy of worrying about. Bring on the baked beans, sponsored silences, and the postcode lottery of respite care, Marie Curie and Macmillan nurses.

Yet, if we want to opt out of these constraints, what are we then? What am I, if I am not brave and battling? Is it the case that notions of 'brave' and 'battling' have only binary opposites such as the 'coward' who 'gives up', or is there another way of regarding the situation, of resisting resilience whilst fighting cancer?

### Resisting Resilience?

As noted above, for me the cancer industry and my role as a patient within it is located within what Giroux (2003) refers to as the

*'...prevailing discourse of neo-liberalism that has taken hold of the public imagination,[where] there is no vocabulary ... to challenge the privatization and commercialization of ... [welfare]...'* (Giroux, 2003, pg 8).

Echoing the point about verbally inert, it is as if we are (I am) denied the space to reframe our (my) own experience and both articulate what and who we are (I am) if we are (I am) neither 'brave' or a 'coward'. Breaking out is difficult finding the space, whether public or private to redefine ourselves is hard to achieve, and I find myself having to adopt a variety of covert tactics. For me this revolves around a number of issues, and my blog identifies several of these, not least my body viz a viz the tumour. Within a narrative that talks of 'battling' cancer, the body becomes the battlefield upon and within which the fight takes place. Yet for me that doesn't make sense, I prefer the notion of the tumour 'battling' (if we have to use that word) me, so much so that I have named him and provided him with a gender and a personality, where refusing to accept the language of personal responsibility, my body was simply in the wrong place at the wrong time.



However, what next? If we accept that we have no language to articulate and define ourselves outside of the powerful hegemonic forces surrounding treatment, health care regimes and our defined roles within them, what comes next- an empty sheet of paper? For me, and for now, that might be enough. It is in itself an act, a personal statement of resistance and rebellion.

However, it also the case that through acknowledging and making the case that we are devoid of language creates the space for new language, new ideas and different ways of knowing, being and thinking about having cancer to emerge. As I note in my blog, I am at that stage at present. For now, knowing that '...*what is out there isn't enough...*' IS enough. It is the start of my act of rebellion and resistance. Others might be more creative in articulating what I find difficult to express. Although expressed and felt personally, the language of cancer and resisting resilience needs to be a shared one, with which others may be more fluent. For now It is enough to know that there is a blank page on which it possible to (re)write those definitions and ideas.

## References

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