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My Body/my calamity. My body/my dignity[1]
The role of autobiographical writing as a therapeutic and ethical strategy for dealing with a cancer diagnosis.

Abstract:

I don't need a written statement assuring my survival. My imagination can work to dampen down fear… It can still dream.

— Brenda Walker, *Reading by moonlight*, 221.

This paper interrogates how autobiographical texts narrating the trauma of a cancer diagnosis and its subsequent treatment might be read as sites of therapeutic and ethical intervention. When writing about the physical and psychic injury caused by a potentially life-threatening disease, an author often performs imaginative acts of reclaiming and retelling her or his *own* story, and in so doing challenges and resists culturally reductive and unethical readings of the ill body as medicalised, marginalised or stigmatised.

In writing about the impersonalisation often afforded to patients in biomedical settings and discourse, an author of a creative text can re-imagine and re-write this experience employing the literary trope of an agentic and integrated self who successfully reconfigures and transforms the personal crisis. In textually representing the self as a direct agent in the renovation process, an author can create a new context where a sense of mastery is restored.

Because a cancer diagnosis has the capacity to rupture a person's sense of bodily integrity and orientation, in writing about this trauma an author can often find a strategic means to process and assimilate suffering. Here, the imagination is called upon to convert residual distress and fragmentation into a coherent and meaningful story.

In a post-Freudian context where the "talking cure" has given prodigious rise to the "writing cure" the need for someone to share in the testimonial enterprise still remains vital for the enactment of a therapeutic process. In this sense, it is the reader of an illness narrative who performs the crucial function of witness. This kind of literary encounter works to create an ethics of care founded on empathic reading practices, and it is in this interpretive and recuperative space that healing is made possible.

Biographical Note:

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Keywords:

Trauma – illness – narration – agency – writing– ethical intervention –

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Overview

In responding to her cancer diagnosis, Susan Sontag offers a profound insight into the traversed space from wellness to illness:[2]

> 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. (1991: 3)

In order to navigate a way back from 'that other' place, writers often draw on literary practices as a strategic means of orientation. There are increasing accounts of authors telling singular experiences of illness, and these narratives are often called autopathographies. Anne Hunsaker Hawkins highlights one of the primary functions of writing this kind of genre; 'patients not only restore the experiential dimension to illness and treatment but also place the ill person at the very centre of that experience' (1999: 128). She also observes that this mode of narration not only situates illness and its treatments within the author's life, but also links them with 'the meaning of life' (128).

Accordingly there has been an observable narrative shift in the twentieth century, as Schultz and Holmes point out, where 'cancer exceeded its discursive boundaries as a biological entity and became the focus of intense cultural interest' (2009: xi). They argue that the 'shifting relations between patients and medical practitioners' helped promote 'the flowering of cancer narratives' (xi). Increasing emphasis on the autonomy of patients and a 'resistance to the authority of the medical gaze or the inhumanity of medicalized settings' (Shultz and Holmes 2009: xi) has also motivated marginalised subjects to take up speaking positions. Often for a writer, the most instinctive recourse when encountering hostile and injurious space is to use words as a defence. Anatole Broyard highlights this kind of impulse to write about illness rather than suppress his feelings in the opening pages of *Intoxicated by my illness*: 'when you learn your life is threatened, you can turn toward this knowledge or away from it. I turned toward it' (1993: 3). This turning towards and the articulation of a personal threat might be read as an ethical act when writers choose words to bespeak suffering.

Trauma of illness

However, to turn toward the knowledge of cancer is to encounter the trauma of uncertainty. In confronting her diagnosis Dorothy Porter signals the initial sense of devastation in her poem 'Ninth Hour':

> I have
> come to a river
> where only pain
> keeps its feet
> I have come to a bridge
> of dissolving bone.

Porter's imagery of dissolution and dislocation represents commonly registered feelings among those directly confronting the disease. She invokes here what David Morris astutely observes as the social phenomenon when 'Illness threatens to undo our sense of who we are' because 'its darkest power lies in showing us a picture of ourselves—false, damaged, unreliable, and inescapably mortal'— noting that this is something we 'desperately do not want to see' (2000: 22).

Like Porter's portrayal of the fragile self, writers who live with the trauma of a protracted cancer experience understand that it 'can wreck the body, unstring the mind, and paralyze the emotions' (Morris 2000: 22). Philip Hodgins' poem 'Leaving hospital' poignantly reflects the psychic and bodily rupturing of a person confronting this sense of annihilation and alienation:

> On the steps I felt the hospital's immensity
> behind me. I thought how this blood, this
> volition would bring me back here to die
> in stages of bitterness and regret. (1986: 7)

In his depiction of an abject and mortal self, Hodgins indexes one of the central threats that illness poses because it confronts us with 'a real loss of control that results in our becoming the Other whom we have feared' (Gilman 1998: 2). To become *the Other* is to become the antithetical embodiment of what society highly values: productivity and participation. Instead of the body enacting the utilitarian story of efficiency and continuity, the illness story initially performs disruption and disorientation. As sociologist Arthur Frank describes it, 'the illness story begins in wreckage, having lost its map and destination' (1995: 164). Hence many of the autopathographies that produce accounts of serious illness ultimately employ tropes that represent a lost destination needing to be re-mapped or re-invented. Again, Broyard advocates for writing functioning as a crucial strategy in first containing (and then potentially re-imaging) this sense of ruin:

> My initial experience of illness was as a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into narrative. Always in emergencies we invent narrative. We describe what is happening as if to confine the catastrophe. (1993: 19-20)

Writing as a therapeutic intervention

This notion of textually confining and re-casting catastrophe using the narrative resources of poetry and prose is promoted in Virginia Woolf's autobiographical essay 'A sketch of the past.' Here she offers an insight into the role of writing in processing trauma:

> [A] shock is at once followed by a desire to explain it… It is only by putting into words that I make it whole; this wholeness means that it has lost its power to hurt me; it gives me, perhaps because by doing so I take away the pain, a great delight to put the severed parts together (2002:12-13).

The kinds of traumatic severing and fragmentation Woolf alludes to are multiple and complex. As Harris notes, '[t]he creative writer contends with various types of

fragmentation—temporal, intrapersonal, interpersonal, sensory, ontological' (2003: 5). And, particularly in the context of the shattering effect of cancer, writers often draw on the 'uses associative language to unify disparate experiences' (Harris 2003: 5). The impersonal features of biomedicine typically exacerbate an ill person's sense of fragmentation as they are often positioned as a case report whose voice is silenced. Expressive writing enables an alternate position where authors can re-cast themselves as articulate protagonists rather than a stigmatised medical statistic. In this sense writing might be read as a therapeutic intervention.

Kaufman and Sexton pose the important question: 'What is it about a narrative that makes writing therapeutic?' (2006: 275) And in determining an answer they point to the benefit that comes from creating a narrative that 'helps makes sense of an upsetting event'. In writing about illness a person may find their trauma becomes more 'organized', and that they are able to gain a 'new meaning' (275). Lengelle and Meijers build on this idea by suggesting that writing functions as a therapeutic modality when it enables a person to 'work toward a more life-giving perspective' which 'may include a shift in perspective, acceptance, or meaning found/constructed' (2009: 59). In this sense it could be argued that 'both writing and psychotherapy provide an opportunity' for an author 'to create a 'second story' that makes sense of experience, especially when a life-threatening illness has suddenly removed all sense of control' (Rickett et al 2011: 265).

In the process of designing and narrating a story of illness a writer may find that these activities are 'purgative, reconstructive, integrative, transformational' because, as Marilyn Chandler suggests, 'the basic requirements of narrative – pattern, structure, closure, coherence, balance – all engage a writer in creating a whole out of fragments of experience' (1989: 6). Because a cancer diagnosis can be destabilising and the invasive treatment dehumanising, autobiographical writing offers an opportunity to counter this sense of fragmentation through authoring/producing a coherent and manageable text. Crafting and (re) structuring a sequenced story enables a new context to be created so in this specific sense 'telling, and even more so writing' becomes 'a way of taking control, creating order and thus keeping chaos at bay' (Rimmon-Kenan 2002: 23).

Writing then can become a vital means of re-orientation and re-anchoring oneself in the social order, and Doris Brett expresses this necessity in her memoir *Eating the underworld*:

> In the face of a life-threatening illness, it is as if you live both forward and backwards at once. You crane anxiously into the future, trying to see if it is really there. You look behind you, trying to understand, examine the past. It is like standing at the fulcrum of finely balanced weights. You can see the landscape like a view from the mountain; clearly visible in some directions, obscured in others. And the topographical lines you draw on that landscape are the story lines of your life. You need those lines, because how else will you know where you are? (2001: 185)

Brett's suggestion is that *storying* illness is an essential component/compass in making sense of the radical dislocation caused by a life-threatening disease.

Ethical (re) imagination

When reflecting on the wounding that comes from this dislocation, Frank suggests that 'becoming a communicative body is an ethical end' (1995: 163). In communicating the embodied subjectivity of an illness experience a writer's imagination is called upon to not only re-orientate the self, but also work against negation. Broyard confesses that for an ill person it 'may not be dying we fear so much, but the diminished self' (1993: 25). Brett provides a further insight into the reductive impact of cancer and the intransigent need to still feel grounded:

> Cancer changes people. It is one of those marker events that delineates a 'before' and 'after' in our lives. It forces us to define and redefine ourselves… and it is right that we have changed. As with any descent into a feared and terrifying country—whether it is the country of illness or the country of a grieving heart— we have entered the underworld. And we have eaten of its fruit (2001: 390).

Writing about the particular grief of the underworld and the re-surfacing from this space might be read as an ethical act where an author reclaims and asserts the value and meaning of her or his *own* lived experience. Frequently the voice of an ill person struggles for utterance in the medical sphere, and medical practitioner Miles Little identifies one of the central challenges: 'Patients offer stories. Doctors take histories. They interrupt, direct, edit, reinterpret and truncate' (2005: 210). Another concomitant problem around silencing is that:

> Illness is not presented to the ill as a moral problem; people are not asked, after the shock of diagnosis has dulled sufficiently, what do you wish to *become* in this experience? What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it? (Frank 1995:159)

Implied in Frank's observation is the notion that autobiographical writing can function as a rhetorical space of *becoming* where an author can ethically answer these and other kinds of questions, and in so doing change the power differential so that their own perspective is privileged. At this point writing can become a form of resistance, and Audre Lorde's *The Cancer journals* serves as an illustration of this kind of activism. She says of her illness and liberation:

> I had to remind myself that I had lived through it, already. I had known the pain, and survived it. It only remained for me to give it voice, to share it for use, that the pain not be wasted (1980: 16I).

Explicit in Lorde's observation is the integral act of authorial truth telling, and the possible transformation of pain because of the ethical/political stance of a writer choosing to speak on their *own* terms.

Transformation

Because illness forces a breakdown in the linear plot of wellness, writing provides an opportunity to (re) conceptualise and (re) produce *a cathartic* narrative. As Kearney notes, '[c]atharsis is the chiasmus where poetics and ethics meet. And where pain finds-sometimes-some relief' (2007: 64). At this juncture the *writerly* body becomes more than the diseased body, enacting a psychic healing that reflects the movement

'from a singular self, frozen in time by a moment of unspeakable experience, to a more fluid, more narratively able, more socially integrated self' (Anderson and MacCurdy 2000: 7). Central to the enterprise of narrating illness is an author's belief 'that the act of writing in some way seems to facilitate recovery; the healing of the whole person' (Hawkins 1999: 129). The trajectory that many *healing* narratives typically follow is a representation of the psychosocial (not necessarily physical) redemption for the writer. Again, Lorde says 'I have gained from the very loss I mourn… . I would never have chosen this path, but I am very glad to be who I am, here' (2006**:** 79). Narratives that chart psychical healing are founded on the belief that an author is able to navigate and forge a new paradigm from the reappraised vantage point that reflective writing enables. This concept of a narratively reconstituted circumstance/self is beautifully evoked by Brenda Walker's transformation metaphor in her illness memoir *Reading by moonlight*:

> … make an honest platform of story in your mind, like a raft, using the sound and timber of everything you have loved and read…. You can stand on it like Robinson Crusoe and look back at the sight of your own shipwreck and say to yourself, as he did, grateful for being able to say it 'I am here, not there' (2010: 221).

In talking about the kind of positive translocation that Walker's metaphor represents, I am reminded of one of Foucault' statements: 'I would like it to be an elaboration of the self by the self, a slow and arduous transformation through a constant care for the truth' (1989: 461). While the construction and disclosure of truth is the ethical and *individual* task of an author, there is a very particular sense in which stories are *social*, that is 'they are told *to* someone, whether that person is immediately present or not' (Frank 1995: 3). While the role of a reader's imagined and anticipated empathic identification with storied illness might assist the author in (re) imagining and (re) establishing an agentic voice, their ultimate potency comes from the resurrective moment of bearing witness to their own writing as the final coda of Porter's 'Ninth Hour' signifies:

> I am not here alone
> Do you hear
> the fighting hiss
> of this geyser
> in me?
> I stand my ground
> in the undaunted spray
> and company of my own words.

Dialogic and interpretive practice

I am conscious that when I both read (and hear) the 'undaunted spray' of a writer's cancer experience, I may offer to her/him a dialogic space outside of the dominant model of biomedicine. This is an important ethical contribution/intervention as the biomedical model is often critiqued for positioning itself as a universal 'grand narrative' that privileges scientific/rationalist discourse above the personal, creative and localised narrative of an *individual*. In engaging with autopathographic texts that

challenge and subvert a dominant hegemony, as a reader I can become part of a dynamic process that receives/creates new knowledge/s and new understanding/s about illness. In my reception of these storied performances I am taking part in the important work of expanding the epistemological frame around illness that has previously been so narrowed by medicine's traditional and empirical focus on identifying and treating disease rather than accommodating, promoting and restoring the *singularity* of patient storytelling.

By reading autobiographical acts that focus on the psychosocial aspects of illness, I am also part of a process that acknowledges and values a writer's construction and transmission of *personal* meaning/s – that is, the making and re-making of the self. Identity formation can be profoundly ruptured by a cancer diagnosis, so to textually renovate or repair the self in the imagined (and real) company of a compassionate reader may enhance a writer's capacity to ethically negotiate and exchange a coherent life story. Because cancer is a disease that can radically mark the body it has the capacity to render a sense of bodily shame and engender feelings of abjection. Yet, when I read an account of such feelings of isolation and marginalisation, my reading practices can symbolically and rhetorically bridge this sense of separation through the inter-subjective moments *shared* between writer and reader.

Trisha Greenhalgh, professor of Primary Care at University College London, draws on the work of Mikhail Bakhtin to describe what might happen in an ideal inter-subjective medical experience: 'in a Bakhtinian framing of clinical interaction, the role of the clinician is to provide the subjective "otherness" for an interactional narrative in which the patient will construct, and make sense of, his or her illness narrative' (2006: 21). What I would argue is that this model also serves as an ethical exemplar for what might also happen in the space when the *readerly* self serves as witness to the writer's/patient's testimony. While Frank argues that '[t]estimony is complete in itself', he draws the important conclusion that 'it requires commentary in order to be transformed into a social ethic' (1995: 145). Being a reader who then analyses and comments on autobiographical testimonial projects through public discourse means that I can partner with a writer and enable such a transformation to take place. If I choose this type of engagement, it might also mean that I take on a particular kind of responsibility.

In commenting on the responsibilities of health professionals to listen to patient stories, medical practitioner and educator Rita Charon also highlights what I see as my role the ideal reader of such stories:

> Narrative ethics exposes the fundamentally moral undertaking of selecting words to represent what before the words were chosen was formless and therefore invisible and unhearable. It is the very act of fitting language to thoughts and perceptions and sensations within the teller as to let another "in on it" … that constitutes the moral act (2006: 55).

This 'moral act', or in Frank's terminology this 'ethics of listening', is not always an easy task because '[o]ne of the most difficult duties as human beings is to listen to the voice of those who suffer' (1995: 25). In keeping company with particular voices that suffer we are confronted by our own threatened mortality. Yet beyond the purview of

this latent fear, lies a generative dividend; that in 'listening for the other, we listen for ourselves' (Frank 1995: 25). Here in the dignified encounter with another person's inscribed words we find an ethics of care contingent upon the *presence* of a teller and a listener because, as Frank reminds us again, 'there is no such thing as a self-story… only self-other-stories' (1995: 163).

This kind of reciprocity where dialogic and interpretive practice can (re)embody calamity as something other is poignantly dramatised in Czeslaw Milosz's poem 'Readings':

> it is proper that we move our finger
> Along letters more enduring than those carved in stone,
> And that, slowly pronouncing each syllable,
> We discover the true dignity of speech. (2003: 262)

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Endnotes

[1] Part of the title for this paper was tangentially inspired by Jean Améry's work.

[2] My interest in the traversed space from wellness to illness, and the therapeutic role writing might play in restoring a person's sense of agency is partly informed by my role as co-ordinator for *The New Leaves* creative writing project. Our chief research aim was to look at the relationship between writing and well-being for people experiencing a life-threatening illness.