Spectrality, Strangeness and Stigmaphilia: Gothic and Critical Disability Studies

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Let us not mince words: representations of disability in Gothic literature have most often been toxic, limiting and corrosive. How, then, might there be a case for resurrecting the term as of potential value in the discourse of critical disability studies? In this chapter, I describe the ongoing dangers of Gothic in disability representation, but also argue that in some cases, a Gothic mode of representation can be used to effectively indict suffering ensuing from social and environmental maladaptation. Furthermore, I suggest that a representational mode preoccupied with suffering and estrangement can mesh with increasing scholarly interest in recognising the affective complexity of disability experience, complicating the division between disability and impairment, and contemplating the disorienting temporal structures that can characterise experience within maladaptive environments. I will close by briefly illustrating my argument with reference to texts that use Gothic conventions and intertextualities to explore disability, social exclusion, and impairment. In the process, I will explore the concept of *stigmaphilia*, in two registers, and I will propose the concept "stigmaphilia in a minor key." This chapter makes a case for the value of the sad, the strange, and the spectral.[1]

The perils of a Gothic mode in disability representation

Since the eighteenth century, Gothic can at times be understood less as a genre than a mode occupying other literary genres (Botting 14). While a challenge to define, the texts typically brought under this catholic critical umbrella tend to share characteristic qualities of emotion, time, and space. The emotions its protagonists typically feel include horror, terror, paranoia and melancholy (Smith 84; Punter 184; Botting 3). Readers have a different response (see

Spooner and Jones), so my comments here apply to the intra-textual worlds engendered by the fictions. Within these textual worlds, fraught emotion colours the experience of both space and time. Gothic often features claustrophobic spaces of confinement, febrile distortions of time, and ancient – even supernatural – threat. Gothic protagonists are often vulnerable, distressed, and struggling within cryptic and hostile conditions. It is immediately clear, then, that such a mode poses multiple dangers for disability representation. I will review three: the Gothic's preoccupation with protagonists enduring misery and isolation; its traditions of depicting unconventional bodies and minds in terms of monstrosity; and the way the mode lends itself to a narrative of an individual fallen into misfortune.

Firstly, Gothic's emphasis on anguish is directly counter to core tenets of disability studies. Founding texts of disability studies scholarship emphasise the need to differentiate disability and impairment. A medicalised view of disability defines it in terms of somatic, cognitive or emotional impairment of function, seeing the cause of disability in terms of an individual's flawed body or mind to be cured or managed through medical intervention. The social model of disability, by contrast, understands disability as a function of a stigmatising society and a maladapted environment (Oliver). Disability is not the same thing as impairment, and neither should mean misery or isolation. There is urgent political necessity to refuse despairing representations of disability (Davis; Finger; Linton; Siebers; Garland-Thomson, *Extraordinary Bodies*; Couser, *Recovering Bodies*). Bill Hughes, for example, justly condemns the "personal tragedy" framing of disability, in which "disabled people are cast as "unfortunates' … in the dark throes of great suffering," in a state of "ruin, a blighted life" (70-71). Such negativity facilitates continued marginalisation of people living with disability, in that it positions disability as a consequence of personal misfortune to be remedied by medicalised cures and paternalistic charity instead of being remedied by making environments more accessible and society less exclusionary. Even more dangerously, a life of

suffering is sometimes seen as devalued life not worth living – and perhaps one that should be taken away, as contemporary debates over euthanasia make disturbingly clear (Finger; Overboe; Torrell; Siebers). There continues to be an urgent need for narratives of disability experience to, as G. Thomas Couser says, "counter the too often moralizing, objectifying, pathologizing, and marginalizing representations of disability in contemporary culture" (606). Indeed, Rosemarie Garland-Thomson argues for "seeing disabled bodies … as extraordinary rather than abnormal," and rightly celebrates literature that hails disability in affirmative ways (*Extraordinary Bodies* 137, 108). The term "disability gain" denotes the way that at times, "conditions of impairment are regarded not as limiting or crippling but as enabling new epistemological and political forms" (Davidson, "Cripping Consensus" 433). In its relentless interest in fear and distress, Gothic seems diametrically opposed to the important political goal of countering negative representations of disability.

Secondly, many Gothic texts abound in ideologically poisonous representations of somatic or cognitive variation in terms of monstrosity. The term is etymologically rooted in the words *monstrare* (to show) and *monere* (to warn), and somatically divergent bodies have been read symbolically since ancient times, as signs of divine warning, markers of warped maternal imagination, or the outward signifier of a flawed genetic code, and more (Shildrick, *Embodying the Monster;* Garland-Thomson, "Wonder to Error" 1996). Diverse though these meanings may be, the term "monster" has rarely had positive connotations. Furthermore, the symbolic repertoire "monster" accretes in any era can be read as a subset of the toxic narrative devices of "discursive dependency" and "narrative prosthesis," identified by David Mitchell and Sharon Snyder, in which disabled characters are used as plot catalysts and metaphorical shorthand for narratives that ultimately support a nondisabled imaginary, eliding the ways disability is socially manufactured and diminishing the experience of people living with disability. Even when such symbolic substitution may seem less hostile – for

example, making a particular disability symbolic of a state of social precarity, rather than evil – it remains highly problematic to recruit disabled bodies to such symbolic labours. As Michael Davidson warns,

> cultural forms depend on a putatively normal body to reinforce regimes of
> national, racial and sexual normalcy while using the person with a cognitive or
> physical impairment as a metaphor for the queer, subaltern, or marginal. **….**
> permitting dominant social structures to be written on the body of a person
> who is politely asked to step offstage once the metaphoric exchange is made.
> (Davidson, "Concerto" 615).

Such symbolic moves erase the social complexity of the lived experience of disability or illness, and reduce people with disability to figures to bolster a nondisabled imaginary. Without question, these representations have risks. It has been suggested that demonising representations of disability and monstrosity might be partially detoxified through readerly self-awareness of Gothic as a fantastical and non-realist mode (Anolik 186). In response to that defence, however, I echo Marie Mulvey-Roberts' cautionary question: "how hermetic is the Gothic container? … The Gothic monster has been a rallying point for cultural, nationalist or religious hegemonies, seldom aware of how they too participate in the creation of monstrosity" (3-4). I, too, would suggest that when Gothic is used as narrative prosthesis, in particular, no degree of critical awareness can wholly purge it of representational risks. In other words, I am not trying to recuperate all Gothic writing.

Gothic's characteristic preoccupation with narratives of injury, deterioration, fall and exile is a third significant problem for conjunctions of Gothic and disability representation. Such tropes are common in illness narration and have long been explored by medical humanities in terms of heroic effort to find meaning in illness and build a new coherence from a life purportedly "shattered" by illness (Charon 1898; cf. Frank, 2013; Hunsaker

Hawkins 1999), although scholars are increasingly challenging the valorisation of "coherence" (Hyvarinen *et al*,; Woods; Whitehead; Wasson, "Creative Manifesto" and "Before Narrative"). Disability studies, in turn, has long resisted these tropes of interrupted life, spurning the rehabilitative arc that accompanies that framing metaphor and questioning the assumption that a state of disability is an unnatural one that must be recuperated and corrected (Overboe 275). Images of illness as exile, of people rendered ghostly by affliction, and mourning for a pre-illness self, can imply that illness or disability are unnatural interruptions to the story of a "normal" body. There are multiple flaws in the interruption trope. It bolsters the dangerous illusion that there is a clear binary between disability/nondisability, failing to recognise not only that health and "autonomy" are temporary and provisional for all of us, but also that the binary of ability/disability is inevitably an unstable one (Goodley; Shildrick, "Critical Disability Studies"). The trope also sets a false binary between a near-perfect prelapsarian state and an anguished fall after the catalytic event, and leaves no space for considering congenital impairments over acquired. Most dangerous of all, as a narrative structure it implictly endorses the notion that disability is synonymous with devastation and is a function of an impaired individual body and mind, rather than a maladaptive environment that must be understood intersectionally. Given these many conflicts, it may seem perverse to consider any value of conjoining a Gothic mode and the representation of lived experience of people with disability. Yet for the rest of this chapter I will try to make a case for exactly that.

Stigmaphilia in a minor key: uses of the Gothic

The term "stigmaphilia" gained currency in the early years of queer theory, when Michael Warner used the term to describe a defiant embrace of a stigmatised position without

acceding to pressures to make that position more conventional, "finding a commonality with those who suffer from stigma, and in this alternative realm to value the very things that the rest of the world despises" (43). The work of Warner, Eve Sedgwick, Judith Butler and others sought to recuperate the abject, taking stigma as a starting point for subversive, collective political action. Sedgwick and others use "queer' rather than "gay and lesbian" partially to denote how these moves are not only about resisting stigmatised alienation as an endpoint, but actually marshalling it for transformative action; not only converting shame to pride, in other words, but also challenging normative social assumptions around monogamy and reproductive futurity, for example. This process is not about desiring stigma per se, but rather about occupying stigmatised positions in the spirit of transformation, creative new solidarities and subversive joy. Sedgwick, for example, observes that stigmatised queer experience is "a near-inexhaustible source of transformational energy," with "experimental, creative, performative force" (609; cf. Butler). As Heather Love says, with some ambivalence, "Although Sedgwick contrasts queer politics to blandly affirmative gay politics, her own discussion of the term 'queer' rests on an 'affirmative reclamation'" (106), as such, this work is about "transforming the base material of social abjection into the gold of political agency" (18). More recently, a similar alchemy is invoked in contemporary "crip theory" (McRuer 35-6; cf. Chen *et al*), which adopts queer theory's deconstructive strategies and stigmaphilic solidarity in the service of challenging not only social conventions but also disability studies' own orthodoxies.

Yet this defiant alchemy may at times require a forgetting. As Love warns, "The premium on strategic response in queer studies" (and I would add, disability studies), "has meant that the painful and traumatic dimensions … have been minimised or disavowed" (3-4). She continues:

I am concerned that queer studies, in its haste to refunction such experiences, may not be adequately reckoning with their powerful legacies. Turning away from past degradation to a present or future affirmation means ignoring the past as past; it also makes it harder to see the persistence of the past in the present. (19)

While respecting how affirmative approaches are of enormous value, Love argues that we must not let suffering be forgotten within these labours: we need "a politics that allows for damage" (Love 162). Anything less than that means forgetting that suffering is not just personal, but historical and social; that trauma, for example, is not just a personal experience but also "a name for experiences of socially situated political violence" (Cvetkovich 3) which continues to reverberate in the present. Sara Ahmed warns:

Ethics cannot be about moving beyond pain … without imposing new forms of suffering on those who do not or cannot move in this way …These histories have not gone: we would be letting go of that which persists in the present. To let go would be to keep those histories present. (216-7).

At times, an affirmative imperative can lead to a state which Deborah Steinberg has, in a different context, called the "I estranged" (123), in profound denial of the reality that loss, grief and mystery can be part of disability or chronic illness experience.

So in discussing Gothic in representations of disability with illness, I propose the concept of "stigmaphilia in a minor key." This is not a counter-definition to the transformative processes McRuer, Warner and Sedgwick celebrate, but is rather a shift in emphasis, in register. In its minor key, stigmaphilia is oriented slightly less towards the telos of transformation, and slightly more towards the initial stage of dwelling with distress. The musical metaphor invokes the way that music in a minor key connotes sadness, grief and a dying fall. I suggest such stigmaphilia in a minor key can describe a writerly affiliation, a

writing craft that deliberately draws close to the textures of pain, shame, and wounds, both stigma and stigmata. It can also describe readerly positions, such as Love's own queer historiography. I find stigmaphilia in a minor key in a wide range of contemporary writers of poetry and prose, including Danielle Pafunda, Leslie Jamison, Christine Friedlander, Johanna Hedva and Sonya Huber. While all these writers differ in important ways, each at times uses an anguished, claustrophobic and tortured register to offer a kind of nightmare realism, an accurate comment on the effects of intersectional structural marginalisation and/or impairment. As I say elsewhere, there is value in capturing the affective labour of endurance, understanding "the present as not yet an event but rather a suspended impasse, a waiting and reaching, within a … particular … social and medical milieu" ("Before Narrative" 5). In valuing the initial dwelling with the image of wound, of *unfinished* injury (including from socially inflicted suffering), I am arguing here that valuable work is done by representations of time frozen and interrupted, images of impasse, stasis, and repetition.

In the context of disability representation, making space for dwelling on particular kinds of disorienting subjective horror can be important in two ways, as I will now discuss. Gothic's preoccupation with distress can itself be a useful counter to forms of positivity that can lead to excluding some people's experience of disability and chronic illness. Furthermore, since the Gothic is characterised by specific idiosyncracies of space and time, it can be deployed as a highly situated mode indicting particular maladaptive environments and the suffering which these spawn.

Disability studies rightly has a deep investment in speaking of impairment in ways that are either neutral or positive, and of focusing on the causes of suffering as social rather than personal. A clear distinction between impairment and disability is central to the social model so influential in founding texts of disability studies (Oliver). Yet it is increasingly recognised that if bodily impairment and suffering are elided from disability studies, then

certain people's experience will be elided. Liz Crow was one of the first to make this argument, warning that while the social model has transformed and indeed saved lives, the orthodoxy of disability positivity can lead to dangerous erasures of people with particular experiences of impairment:

> The experience of impairment is not always irrelevant, neutral or positive. ......
> Many of us remain frustrated and disheartened by pain, fatigue, depression
> and chronic illness, including the way they prevent us from realizing our
> potential or railing fully against disability….we mourn past activities that are
> no longer possible for us. (4-5).

Similarly, Susan Wendell affirms the social model's refusal to equate disability and illness, yet warns that the two categories may overlap for some people in ways that require us to recognise impairment in terms that may well be negative, and illness and disability can coexist. Wendell differentiates "healthy" and "unhealthy disabled," and describes multiple kinds of alienation that can develop between the two groups. People living with disability and chronic illness may be engaged with medical treatment, may wish for medical cure, or may have disabilities that are unpredictable and invisible, and may thus be seen as less credible – not only by healthcare practitioners, but also by fellow disability activists. People with disabling such chronic illness can feel enormous pressure to deny suffering, impairment, and grief. Efforts to nuance the social model with recognition of embodiment have continued. Alison Kafer's "political-relational model," for example, echoes the social model in the way it continues to see the disability as caused by maladaptive environments and a stigmatising society, yet resists a sharp distinction between impairment and disability, understanding *both* impairment and disability as social and refusing to erase "the lived realities of impairment," including the possibility of mourning (6-7). Similarly, Margrit Shildrick describes Critical Disability Studies as emphasising "a new focus on the significance of embodiment; an

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awareness of the workings of the cultural imaginary; a deconstruction of binary thought in favour of the fluidity of all categories; and a recognition that emotion and affect are as important as the material aspects of life" ("Critical Disability Studies" 32). Drawing on queer theory and other theoretical traditions inflected by poststructuralism, approaches such as these share an interest in deconstructing binaries characteristic of ableist and of disability studies discourse, while remaining committed to social reform.

Within a purely social model of disability, distress about impairment may be read as false consciousness, as a person failing to understand that their distress is not due to the impairment but rather to a hostile and stigmatising environment and psycho-emotional disablism, leading to internalised stigma. Without a doubt, this is a common reality. Yet seeing all such distress as "false consciousness" would be highly problematic, in that it would explicitly delegitimate the lived experience of particular people who are already highly marginalised. This is particularly salient in the case when disability coincides with chronic and invisible illness. Havi Carel and Ian James Kidd observe that many such patients already undergo "epistemic injustice" in healthcare, being seen as non-credible sources with regard to their own condition (529). With some people's distress already marginalised in this way within medicalised frameworks, it is a bitter twist if disability studies discourses repeat that erasure. At such moments, a mandatory positivity within disability discourse would inadvertently reinforce a damaging element of medicalised care cultures. Any such parallel is of course deeply ironic, since the positivity of disability studies is necessary specifically to resist medicalisation of impairment. Yet the fact remains that positivity is also central to the idealised affective proprieties of neoliberal patienthood, which involves particular affective imperatives for the ill. A "positive attitude," ranging from faith in a cure to positivity in daily self-management, is held up as both enhancing health and morally laudable (Jain; Ehrenreich; Steinberg; Wasson "Before Narrative"). While such affective discipline can be helpful for

many, at times its price can be estrangement from the "surreal" registers of the body, in Nancy Miller's phrase, in which we may doubt our experiences and feel required to suppress distress (208-9).

These texts are not only valuable for the way in which they flout the positivity imperative that continues to (rightly) characterise much disability studies analysis. They can also be effective in communicating social injustice. Since the Gothic is characterised by confined spaces and disjointed temporality, it can actually be deployed as a highly situated mode lending itself well to indictments of specific maladaptive environments and the suffering they spawn. The disjointed temporalities of a Gothic mode can be apposite for temporalities that can characterise disability and chronic illness, and Gothic representations of claustrophobia and confinement can be apt spatial tropes for describing experiences as mobility restriction in insufficiently adapted built environments, or being immured in Kafka-esque systems for verifying welfare eligibility under neoliberal austerity protocols, or the experience of being contained – even surgically reshaped – within medicalised frameworks of care that pathologise difference.

Vampires, live burial, and flesh made cloth

Next, I will briefly discuss several texts which deploy a constellation of Gothic tropes and a preoccupation with impasse and strange movement in time. In such cases, the Gothic triad of confined space, disjointed temporality, and distressing emotion is deployed here *not* (only) to express hidden anxieties of a culture, that traditional anxiety model of Gothic criticism, but rather as a productive and speculative mode, formulating visions of the human and social (dis)connection (Hurley 6; Wasson, *Transplantation Gothic*).

Ellen Samuels draws on imagery of the living dead to describe her experience of living with the genetic condition Ehlers-Danlos Syndrome, in which the collagen throughout her body is fragile, affecting all her organs, tissues, skin, giving rise to permanent pain and an unnatural appearance of youth. She is a disability studies scholar, and she challenges the imperative to celebrate that continues to be an important strand of disability studies rhetoric. In particular, she wishes to explore the temporal aspects of her experience of both disability and of suffering, and she does this by glossing six negative dimensions of "crip time." "Crip time" has become a precious and familiar term among many of us living with disability. The term originated within disability communities to describe the way things take longer with disability due to disablist barriers, impairment, and other obstacles. The term has also taken on an additional dimension, to challenge assumptions around accelerated society and normative futurity (Kafer). Samuels cherishes these transformative meanings of crip time, but also wishes to speak of the more difficult aspects of time, as she lives it. To that end, she offers supplementary definitions: crip time is "time travel," "grief time," "broken time," "sick time", "writing time," and "vampire time." As part of her challenge to affective propriety, she implies an identification with an iconic Gothic monster.

While the monster trope has almost always been used to radically "other" people in denigrating ways, it has occasionally been used to more positive ends, particularly in the first person. Garland-Thomson, for example, takes this stance when she writes, "Those of us who have been known since antiquity as 'monsters' and more recently as 'freaks' defy the ordinary and mock the predictable, exciting both anxiety and speculation among our more banal brethren" ("Wonder to Error" 1). Here, Garland-Thomson celebrates somatic and cognitive uniqueness from a position of agency. Yet Samuels's essay uses a monster trope not to celebrate, but to mourn. Samuels writes that she inhabits:

vampire time… the time of late nights and unconscious days, of life schedules

lived out of sync with the waking, quotidian world. It means that sometimes

the body confines us to a coffin, the boundary between life and death blurred

with no end in sight. Like *Buffy's* Angel and *True Blood*'s Bill, we live out of

time, watching others' lives continue like clockwork while we lurk in the

shadows. And like them, we can look deceptively, painfully young even while

we age, weary to our bones. (para. 25-28).

Here, intertextualities of popular Gothic and images of atavistic monstrosity combine to

convey a present, past and future made unstable, in temporal disjunctures of impasse,

freezing, repetition, and curse. In Samuels's prose, the characteristic spaces and temporalities

of Gothic are bent to describing body as dungeon, and time as living death. This is

stigmaphilia in a minor key, representing agony without moving too quickly to emphasise its

transformative potential.

My next examples come from Deborah Padfield's collection of short prose reflections

from people living with chronic pain, often alongside disability. The prose appears alongside

photographs co-created with Deborah Padfield. I will consider several excerpts that draw

variously on the tropes of live burial, a body transforming into cloth, and a self becoming

spectral. Almost invariably showing glimpses of partial bodies or objects suspended in a

black field, these images communicate fragility, isolation and grief. Yet these extracts do not

inevitably call forth "personal tragedy" interpretations of an individual disabled due to bodily

impairment, but also describe social isolation within maladaptive environments.

Contributors Stephen Dwoskin and Patrick Dixon draw on the image of live burial in

concrete to describe their experience of physical pain, their social isolation, and their deep

distress (fig. 1). At first, the trope of live burial is deployed to describe physical experience.

Dwoskin says his condition feels like "cement being poured down my throat and filling up

my body and I can't stop it," and Patrick Dixon uses the metaphor to describe radical limitations to movement: "slowly it sets and then you cannot move" (Padfield 108, 81). Yet for both, the metaphor of live burial rapidly morphs to convey not only a physical experience, but also a social plight. Dixon suggests, for example, that his concrete imagery also stem from living in a city ill-adapted for mobility: "It is as though the buildings are closing in, like the density of mixed concrete pouring. The density is not liquid, but solid" (Padfield 108). Ultimately, the trope of live burial comes to signify social exclusion. Dixon continues, "I was trapped in a black isolated space – no one could be in it with me…. That cement suit is me" (Padfield 108). These are funereal structures, marmoreal, but they describe not an ending, but an ongoing state of impasse and stasis. The Gothic imagery not only communicates distress, but captures the affective toil of enduring an insufficiently accommodating space and society.

Fig. 1. Deborah Padfield with Patrick Dixon from Deborah Padfield (2003) *perceptions of pain*. Stockport: Dewi Lewis Publishing: p80. © Deborah Padfield, reproduced by kind permission of Dewi Lewis.

Nell Keddie and Padfield co-create several images to communicate Keddie's experience of living with pain from a crushed lumbar spine, facial pain and disturbed sensation. She describes her back pain in terms of shadows and broken glass (fig. 2): "Glass breaks. … Can you pick it up, piece it together again? Leaving it there is terrible. Glass is very difficult to put back together again" (Padfield 118). Keddie is not despairing, and is

fortified by turning her pain experience into creative work. Yet despite her readiness for transformation, her words and images do not wholly forsake the place of pain. This, too, is stigmaphilia in a minor key. Overlaying images of Keddie's body with shadows and fractured glass, Padfield and Keddie communicate invisible injury, marked on her skin in traces of light and shadow. As her image sequence progresses, the fragmented glass fractures even more minutely, multiplies and spreads, ultimately obscuring much of her flesh.

Fig. 2. Deborah Padfield with Nell Keddie from Deborah Padfield (2003) *perceptions of pain*. Stockport: Dewi Lewis Publishing: p119. © Deborah Padfield, reproduced by kind permission of Dewi Lewis.

To communicate her experience of facial pain and disturbed sensation, Keddie represents her skin and subdermal tissue as dead or unnaturally transformed (fig. 3): "it is as though I can't feel the flesh properly, as though it were not alive … as though it had gone dead … It's very deep, not just the surface. It is as if had turned to cloth" (Padfield 113). She frames her body here in Gothic terms of (un)death and inhuman transformation, her back broken like glass, her face partially dead, her skin turned to cloth. These metaphors powerfully convey her sense of estrangement from her own body. Yet her imagery also

achieves something else, for she looks back at us from within the image. In *Staring,* Garland-Thomson describes the intersection of stare and starer as a complex dynamic within which the staree is not passive, but an agent, with a potential multitude of strategies for choreographing the encounter. Keddie's image conveys some of this agency on the page in her direct gaze back to camera. Yet the twist in Keddie's image is that her image modification has placed one of her own eyes within the Gothicised cloth-space of her face. As such, she gazes back at the viewer from within a wound, an impairment, which she has chosen to make visible. In other words, this digitally manipulated image confronts us from her position within that impairment. She claims our gaze, confronting us from her felt position, and from within the ways her life has been affected not only by the bodily change she experienced but by the social environment which has shaped how that bodily change has come to restrict her. She stares out from within the changed flesh. Her gaze claims recognition of both her suffering and her agency, but *without erasing* the pain. This is stigmaphilia in a minor key.

Fig. 3. Deborah Padfield with Nell Keddie from Deborah Padfield (2003) *perceptions of pain.* Stockport: Dewi Lewis Publishing: p115. © Deborah Padfield, reproduced by kind permission of Dewi Lewis.

In closing, a thought about ghosts. Disability studies criticism has a tradition of

invoking spectres to describe scholarly transgression and power. As McRuer observes,

> some of our most cherished theses demonstrate how invested we are in
>
> haunting. .... Absences that are somehow preternaturally present ... academics
>
> startled by us or refusing to acknowledge our existence – we like, in short, to
>
> *do* the haunting. (199-200).

Yet like any human endeavour, disability studies is also, inevitably, haunted, in the sense that

past human suffering shapes it in ways that cannot fully be witnessed or seen and yet which

continue to be highly salient in the present. This is one of the senses in which Jacques Derrida

speaks of ghosts, in his call for us to be willing to be haunted.

> No justice ... seems possible or thinkable without the principle of some
>
> responsibility, beyond all living present, within that which disjoins the living
>
> present, before the ghosts of those who are not yet born or who are already
>
> dead, be they victims of wars, political or other kinds of violence …. (*Specters*
>
> xix).

Derrida insists that this work must always be understood as both impossible and incomplete,

an imaginative movement that is simultaneously yearning without colonising, a move which

does not cease reaching for the other, yet simultaneously "leaves the other alone, outside,

over there, in his death, outside of us" (*Memoires* 35). In his epilogue to *Crip Theory,*

McRuer recruits Derrida to his closing call for us to imagine a celebratory transgressive

futurity, one in which crip and queer lives are no longer constrained or limited by

normativities (208). I wholeheartedly echo this call. Yet what is downplayed in that epilogue

is the grief that remains at the heart of Derrida's model of spectrality (cf. Harrison; Wasson,

Urban Gothic 159-162). Such emotion continues to sit uneasily with much work of disability studies, both past and present.

Disability and illness are not the same thing, and neither inevitably involves suffering. But sometimes they do coincide, and we need to continue to foster critical frameworks that can recognise and respond to the subtleties of those conjunctions. Gothic textual devices and intertextualities can support efforts to problematise divisions between disability and impairment, and to critique elements of the care context that characterise the experience of many people with disability and chronic illness. Gothic's negativity can communicate damage wrought by structural exclusions afflicting those with disability or chronic illness, including the institutional contexts that find one's experience unintelligible and the economic pressures that render life precarious, and it can transgress established discourses of sanctioned affect in disability representation, without eliding the still-present "ruined state of the social world" (Love 27). That is stigmaphilia in a minor key. Distress can be read not in terms of moral failure or personal tragedy, but as a social index to a wider exclusionary biopolitical environment. For many are indeed rendered spectral, strange or sad.

Works cited

Ahmed, Sara. *The Promise of Happiness*. Durham: Duke University Press, 2010.

Anolik, Ruth Bienstock. "The Infamous Svengali." *The Gothic Other,* edited by Ruth Bienstock Anolik and Douglas L. Howards. Jefferson, NC: McFarland, 2004, pp. 163-96.

Botting, Fred. *Gothic*. London: Routledge, 1996.

Butler, Judith. "Critically Queer." *GLQ,* vol. 1, no. 1, November 1993, pp. 17-32.

Carel, Havi and Ian James Kidd. "Epistemic Injustice in Healthcare." *Medicine, Health Care and Philosophy,* vol. 17, no. 4, 2014, pp. 529-540.

Charon, Rita. "Narrative Medicine." *Journal of the American Medical Association,* vol. 286, 2001, pp. 1897–902.

Chen, Mel, Alison Kafer, Eunjung Kim, and Julie Avril Minich. "Crip Genealogies." 15 March 2017. www.disabilitystudiesnetwork.gla.ac.uk/2016/12/22/cfp-crip-genealogies/

Couser, G. Thomas. "Disability, Life Narrative, and Representation." *PMLA,* vol. 120, no. 2, 2005, pp. 602-606.

Couser, G. Thomas. *Recovering Bodies.* Madison: University of Wisconsin Press, 1997.

Crow, Liz. "Including All of Our Lives." 1996. www.roaring-girl.com/wp-content/uploads/2013/07/Including-All-of-Our-Lives.pdf

Cvetkovich, Ann. *An Archive of Feelings*. Durham: Duke University Press, 2003.

Davidson, Michael. "Concerto for the Left Hand." *PMLA,* vol. 120, no. 2, March 2005, pp. 615-19.

Davidson, Michael. "Cripping Consensus." *American Literary History,* vol. 28, no. 2, 2016, pp. 433-453.

Davis, Lennard, *Enforcing Normalcy.* London: Verso, 1995.

Derrida, Jacques. *Mémoires*, translated by Jonathan Culler, Cecile Lindsey and Eduardo Cadava. New York: Columbia University Press, 1986.

Derrida, Jacques. *Specters of Marx*. 1993. Trans. Peggy Kamuf. New York: Routledge, 1994.

Ehrenreich, Barbara. "Welcome to Cancerland." *Harper's Magazine*, vol. 303, no. 1818, November 2001, pp. 43-53.

Finger, Anne. *Past Due.* 1990. London: Women's Press, 1991.

Finkelstein, Vic. "Outside, 'Inside Out'." *Coalition,* April 1996. disability-studies.leeds.ac.uk/files/library/finkelstein-Inside-Out.pdf

Frank, Arthur. *The Wounded Storyteller*, 2nd ed. Chicago: University of Chicago Press, 2013.

Friedlander, Christine. *Avant Gauze.* Portland, OR: Magic Helicopter Press, 2016.

Garland-Thomson, Rosemarie. "From Wonder to Error." *Freakery,* edited by Rosemarie
      Garland-Thomson. New York: NYU Press, 1996, pp. 1-22.

Garland-Thomson, Rosemarie. *Extraordinary Bodies.* New York: Columbia University Press,
      1997.

Garland-Thomson, Rosemarie. *Staring.* Oxford: Oxford University Press, 2009.

Goodley, Dan. Dis/ability Studies. London: Routledge, 2014.

Gordon, Avery. *Ghostly Matters.* Minneapolis: University of Minnesota Press, 1997.

Harrison, Paul. "After Affirmation." *GeoHumanities,* vol. 1, no. 2, 2015, pp. 285-306.

Hawkins, Anne Hunsaker. *Reconstructing Illness,* 2nd ed. West Lafayette: Purdue University
      Press, 1999.

Hedva, Johanna. "Sick Woman Theory." *Mask Magazine,* January 2016.
      www.maskmagazine.com/not-again/struggle/sick-woman-theory

Huber, Sonya, *Pain Woman Takes Your Keys.* Lincoln: University of Nebraska Press, 2017.

Hughes, Bill. "Fear, Pity and Disgust." *Routledge Handbook of Disability Studies,* edited by
      Nick Watson, Alan Roulstone and Carol Thomas. London: Routledge, 2012, pp. 67-
      77.

Hurley, Kelly. *The Gothic Body*. Cambridge: Cambridge University Press, 1996.

Hyvärinen, Matti, Lars-Christer Hydén, Marja Saarenheimo and Maria Tamboukou. "Beyond
      Narrative Coherence." *Beyond Narrative Coherence*, edited by Matti Hyvärinen,
      Lars-Christer Hyden, Marja Saarenheimo and Maria Tamboukou. Philadelphia: John
      Benjamins, 2010, pp. 1-15.

Jain, S. Lochlann. "Cancer Butch." *Cultural Anthropology,* vol. 22, no. 4, November 2007,
      pp. 501-538

Jamison, Leslie. "Grand Unified Theory of Female Pain." *VQR,* 2014.

     www.vqronline.org/essays-articles/2014/04/grand-unified-theory-female-pain

Jones, Timothy, *The Gothic and the Carnivalesque in American Culture.* Cardiff: University

     of Wales Press, 2015.

Kafer, Alison, *Feminist, Queer, Crip*. Bloomington: Indiana University Press, 2013.

Linton, Simi, *Claiming Disability.* New York: NYU Press, 1998.

Love, Heather, *Feeling Backward* . Cambridge: Harvard University Press, 2007.

McRuer, Robert, *Crip Theory*. New York: NYU Press, 2006.

Miller, Nancy K. "The Trauma of Diagnosis." *Configurations,* vol. 22, no. 2, Spring 2014,

     pp. 207–23.

Mitchell, David and Sharon Snyder. *Narrative Prostheses.* Ann Arbor: University of

     Michigan, 2000.

Mulvey-Roberts, Marie. *Dangerous Bodies.* Manchester: Manchester University Press, 2016.

Oliver, Michael. *The Politics of Disablement*. Basingstoke: Macmillan, 1990.

Overboe, James. "Ableist Limits on Self-Narration." *Unfitting Stories,* edited by Valerie

     Raoul, Connie Canam, Angela Henderson and Carla Paterson. Waterloo, Ontario:

     Wilfrid Laurier University Press, 2007, pp. 275-282.

Padfield, Deborah. *perceptions of pain.* London: Dewi Lewis, 2003.

Pafunda, Danielle. *Manhater*. Kingston, RI: Dusie Press, 2012.

Punter, David. *Gothic Pathologies*. Basingstoke: Macmillan, 1998.

Punter, David. *The Literature of Terror,* vol. 2, 2nd ed. Edinburgh: Pearson, 1996.

Samuels, Ellen. "Six Ways of Looking at Crip Time." *Disability Studies Quarterly,* vol. 37,

     no. 3, 2017. dx.doi.org/10.18061/dsq.v37i3.5824.

Sedgwick, Eve Kosofsky. "Queer Performativity." 1993. *The Novel,* edited by Dorothy J.

     Hale. Oxford: Blackwell, 2006, pp. 605-621.

Shildrick, Margrit. "Critical Disability Studies." *Routledge Handbook of Disability Studies,*
    edited by Nick Watson, Alan Roulstone and Carol Thomas. London: Routledge, 2012,
    pp. 30-41.

Shildrick, Margrit. *Embodying the Monster.* London: Sage, 2002.

Siebers, Tobin. "In the Name of Pain." *Against Health,* edited by Jonathan Metzl and Anna
    Kirkland. New York: NYU Press, 2010, pp. 183-94.

Smith, Andrew. "Rethinking the Gothic." *Gothic Studies,* vol. 4, no. 1, 2002, pp. 79-85

Spooner, Catherine. *Postmillennial Gothic*. London: Bloomsbury, 2017.

Steinberg, Deborah Lynn. "The Bad Patient." *Body and Society,* vol. 21, no. 3. September
    2015, pp. 115-143.

Thomas, Carol. *Sociologies of Disability and Illness.* Basingstoke: Palgrave, 2007.

Torrell, Margaret Rose. "Interactions." *Life Writing* vol. 13, no. 1, 2016, pp. 87-10. p. 93.

Warner, Michael. *The Trouble with Normal.* New York: Free Press, 1999.

Wasson, Sara. *Transplantation Gothic*. Manchester: Manchester University Press,
    forthcoming.

Wasson, Sara. "Before Narrative: Episodic Reading and Representations of Chronic Pain."
    Medical Humanities, July 2018, Online First, 5 January 2018.
    mh.bmj.com/content/early/2018/01/11/medhum-2017-011223.

Wasson, Sara. "Creative Manifesto: Translating Chronic Pain." 2017. *Translating Chronic
    Pain,* AHRC Research Network, Lancaster University
    wp.lancs.ac.uk/translatingpain/creative-manifesto/

Wasson, Sara. *Urban Gothic of the Second World War*. Basingstoke: Palgrave. 2010.

Wendell, Susan. "Unhealthy Disabled." *Hypatia,* vol. 16, no. 4, 2001, pp. 17-33.

Whitehead, Anne. "The Medical Humanities." *Medicine, Health and the Arts,* edited by

    Victoria Bates, Alan Bleakley, and Sam Goodman. Abingdon: Routledge, 2014, pp.

    107–27.

Williams, Raymond, *Marxism and Literature.* Oxford: Oxford University Press, 1977.

Woods, Angela. "Beyond the Wounded Storyteller." *Health, Illness and Disease,* edited by

    Havi Carel and Rachel Cooper. Durham: Acumen, 2013, pp. 113-128.