

## Imaginary Investments: Illness Narratives Beyond the Gaze

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Samuel Beckett, in his partly-autobiographical novel, *Murphy* (1957), uses his narrator to describe a series of hospital encounters intended to uncover the medical condition underlying a cardiac complaint. Without success, he tells the reader, his "irrational heart" was "inspected, palpated, auscultated, percussed, radiographed and cardiographed" (3). Although Beckett would not have described *Murphy* as an illness narrative, he captures very accurately the dominant perspective on the history of the modern medical encounter. Murphy is subject to the objectifying gaze of medical professionals and their visual technologies while at the same time he is characterised as the "irrational" patient solely defined by his specific pathology. This positioning of medical authority and patient submission is precisely the totalizing relationship of the clinical gaze as determined by Foucault in *The Birth of the Clinic*. Foucault's conceptualization of a paradigm shift in Western medicine has been endorsed by studies of nineteenth- and twentieth-century clinical medicine, which describe a significant reorientation in the balance of power between patient and doctor around 1800 (Ackerknecht; Fissell; Jewson) and the growing dominance of an 'object-oriented' medical cosmology. It is this construction of the medical encounter and the growing dominance of biomedicine that Foucault seeks to chronicle that scholars of illness narratives have long sought to overturn. In this scholarship patient narratives are neither irrational nor passive but instead actively and subjectively valuable stories of illness that give both meaning and context to the conditions of illness from the patient's perspective. While the methods by which such narratives might be analysed and interpreted have led to scholarly disagreement, Arthur Frank captured a consensus when he argued that "narratability means that events and lives are affirmed as being worth telling and thus worth living. Being narratable implies value and attributes reality" ("Why Study" 111). Despite its efforts to reassess, and indeed to respect and value the patient story, illness narrative scholarship has rarely sought to do so by rejecting the orthodoxy of Foucault's vision of the emergence of the clinical gaze that led originally to the dismissal of the patient perspective that it seeks to re-inscribe. Critics have, of course, followed Habermas in his judgement that Foucault's reading of the historical evolution of the modern hospital was overbearingly structural and lacking in specific example (Kennedy, *Revising* 9-10; Rylance, 256; Jones and Porter). However, there has been little attempt to consider whether those aspects of the clinical medical encounter that Foucault claimed had been rejected by the beginning of the nineteenth century did, in fact, disappear or whether they were maintained, and continue to be so, in illness narratives of varying type and form.

*The Birth of the Clinic* argues that key to the emergence of the clinical gaze was the loss of a "visionary space" (Foucault x) which is evoked through a language both fantastical and myth-making, a language that both gave room for the imagination and privileges the imaginative, historicised metaphor as providing access to truths about medical encounters and illness. These are the "imaginary investments" (Foucault xii) from which the future of medical encounters depart. For Foucault a change occurs around the beginning of the nineteenth century whereby the visionary space becomes encapsulated entirely within the body of the patient and is thereafter wrestled with and ultimately controlled by the gaze (and the narrative that inscribes

the gaze) of the medical professional. This difference, Foucault argues, and the progress of his argument is vital here, "is both tiny and total. For us, it is total" (xi). But what if the difference in "imaginary investments" were simply tiny? Indeed what if there *was* little discernible difference?

This article argues that the "imaginary investments" that Foucault so offhandedly rejected did not disappear into the imprisoning cavities of the human body to be made subject to the clinical gaze. By thinking about the narratives produced by family members – actors beyond the binary of the doctor and patient – it suggests these "imaginary investments" continued to perform their myth-making and imagining in disparate medical narratives which undermine the gaze's totality to consider illness narratives as writing and their contribution to both the historical record of illness and the literary canon of somatic fictions. Although these fugitive narratives, and their metaphors of resistance, have not previously been considered in medical humanities scholarship, their existence can be read as evidence of a continuing project of communal imaginative acts of history-making that offer an alternative to the present understanding of narrative praxis in the field. Just as Foucault examined third-person narratives – the doctor's – describing the medical encounter, this article explores a further set of third-person narratives – that of the family member as carer – commonly ignored in the medical humanities.

Building on a literature that draws attention to the role of the family in structuring medical care, and on scholarship that explores how the medical encounter invariably involved more actors than just the patient and the doctor, the article places narratives generated by family members and carers written in 2010 and 2011 in South Wales, UK, at the centre of its analysis. It offers a unique interdisciplinary perspective that brings into dialogue sociological and historical studies with literary theory. By doing so the article extends the reach of present writing on illness narratives and offers a significant new model for the assessment of writing about illness across disciplinary boundaries. While scholars have drawn attention to how the sick and their families negotiated care in the early modern medical marketplace, families remained important in making decisions about the nature of the medical encounter in the nineteenth and twentieth century. Families were widely consulted over illness and exchanged advice and treatments, while medical practitioners would often only address female patients through their fathers, brothers or husbands. Families were crucial actors, as studies of the Victorian asylum and workhouse show, in determining when institutional care was necessary and the boundaries of that care, as well as what happened to the patient's body after death (Porter and Wright; Wright; Hurren). Equally sociological studies of illness narratives in the 1980s and 1990s pointed to the support networks that benefit patients (Zola; Viney and Bousfield). Just like the patient, families and those involved in these networks constructed their own narratives, using them to negotiate the medical encounter and to make sense of illness and their experiences.

Narratives of illness and the medical encounter that reveal their resistance to the clinical gaze take different formal structures and can be found in varied contexts. They exist both within the classic medical encounter (between doctor and patient) and also at a remove from it (in the writing of patients' family members and carers, for example). What they share, however, is an articulation of that visionary space, often evoked through metaphorical and imaginative connection to already existing histories and literatures, that Foucault and others argue was redacted into the patient body and laid claim to only by biomedical authority. Such narratives invest in the authenticity of imagined encounters outside the clinic or hospital; encounters with alternative

modes of reality situated both within history and the objective/subjective binary that occupies medical exchanges rather than simply within the later. One example of this alternative imaginative landscape is the 2011 narrative of a patient's wife (Marie) who, intent on spending the night in visitor accommodation on a hospital site still largely imagined by contemporary visitors as Victorian in its architectural formation, leaves the clinical space of the patient bedside in search of her room:

I realised I had to walk back to the accommodation block in the dark so I left as soon as the football started and returned to the silent room. I felt glad that David was settled and relaxed. He had his place, he was meant to be there. I walked back through the modern part of the building which was now deserted, and out to the dark, empty walkway. I noticed to my right that there was a modern block of some considerable size stretching away from me in a part of the hospital I had not yet seen. Low, warm lights were glowing against the dark night. That must be where the bald children were. The corridor in the accommodation block was eerily quiet. Trips to the communal toilet were quite scary. I sensed the presence of others but saw no-one.<sup>2</sup>

Marie's narrative is particularly interesting as it hints at a subtle and disquieting surveillance that might easily be read as exemplifying the clinical gaze and efforts to fashion the hospital as an disciplined clinical space. Yet its reference point is neither the modern hospital nor its culture of observation but rather than being clinical *per se* it is evocative of late-nineteenth century ethnographic writing suggested to the author by the Victorian architecture of many of the hospital buildings, which after 1850 were increasingly designed around the principles of order and surveillance. This medical encounter can be located within the linguistic and thematic organization of mid-late Victorian urban ethnographic journalism, Charles Dickens's and W.T. Stead's amongst the best-known of these types, as the author registers the alien nature of the hospital geography, their own displacement in that space, and the radical difference between themselves and other imagined yet unseen inhabitants. In imagining the hospital in this way, the author echoes the sense of alienation experienced by the families of Victorian hospital patients and the unfamiliar geography of the hospital, access to which was carefully controlled through visiting hours and how the internal space of the hospital was organised. The particular reification of young cancer sufferers as the much more uncanny "bald children" strikingly separates the author from any sense of recognition or empathy with those also visiting or admitted into the hospital. This is enforced primarily through the repetitive "he had...he was" that implies difference as much as it is supposed to assert satisfaction.

Further than the ethnographic journalism that acts as historic inter-text this illness narrative also evokes a fictional account of alienation that was already a further mediation of ethnography. In his 1853 novel *Bleak House*, Dickens uses his experience of ethnographic journalism to imagine the experience of the slum-child Jo in the alienating environment of London's East End: "It must be a strange state to be like Jo! To shuffle through the streets, unfamiliar with the shapes and in utter darkness to the meaning, of those mysterious symbols, so abundant over the shops, and at the corners of streets [ . . . ] to feel that it would be perfectly true that I have no business here, or there, or anywhere; and yet to be perplexed by the consideration that I am here somehow, too, and everybody overlooked me" (124). The resonance between Dickens's reflections on Jo and the contemporary narrative is striking: both suggest

personal exclusion and employ the image of darkness to enhance the solitude that such exclusion engenders. There is, though, a more specific parallel that goes beyond this general sense of alienation. Dickens is suggesting an alienation that comes about through the absence of language (Jo's inability to read) and is also putting in place here the denial of access to care, particularly medical care, from which Jo (already a carrier of disease) will later suffer. Marie's story emerges in this intertextuality with Dickens as particularly aligned to concerns both about the writing of an illness narrative and the accessibility to the pastoral support of the clinical space. While this parallel may not be one consciously introduced by the writer of the contemporary narrative, there is nevertheless a similar aesthetic at work in both; a Dickensian aesthetic that recalls the meaning of aesthetic as knowledge emerging from the body (Eagleton, 14; Dixon).

To regard Dickens's fiction as a further imaginative texture within the illness narrative therefore also increases the potential for understanding its own subtle politics. Its sense of alienation is not, when read in the context of *Bleak House*, simply a product of the unfamiliar geography of the hospital, it is also that the author has been, in Dickens's word, "overlooked". The narrative therefore reflects upon the author's own sense of marginalization from the medical encounter, ejected from the bedside into the dark spaces of the outer medical environment which is self-consciously imagined as Victorian. While this may seem to suggest that the narrative itself recognises and even accedes to Foucault's understanding of the powerful clinical gaze, it is important to recognise that the narrative does not place the author only in the position of subject but also as the writer/observer in a deliberate act of imagination into another person's subject position; Dickens the novelist rather than Jo the disenfranchised slum-dweller. The author has power, both as a producer of narrative, and as a writer whose work is in dialogue with layers of other historical and literary writing.

The very existence of this brief story, and its empirical evidence, should act as a reminder that narratives of illness and encounters with clinical spaces are not only constructed at the bedside, or even only within the tripartite structure of patient, doctor and disease, as, in another context, Paul Atkinson has argued (339). Nor do they work within the formulation of the clinic as Foucault conceived it. Rather, they provide alternative forms of knowledge; as our analysis of three varying narratives will show this knowledge is both historically and creatively situated and invested with the myth-making power of the imagination.

### **Situated Narratives**

Scholarly work on illness narratives is quick to situate them within a range of categories which, scholars argue, emerge from the themes and structures of the narratives themselves. Mike Bury, for example, finds illness narratives in three distinct forms: contingent narratives that deal with the effects of illness on everyday life, moral narratives that deal with personal change and selfhood, and core narratives that focus on the relationship between personal illness experience and its cultural meanings (268-80). All of these categories are essentially sociological – they oscillate between and across a personal and social politics of identity. Similarly, Frances Rapport, ostensibly offering fresh perspectives on the methodological study of illness narratives, finds that stories of illness are best "broken down" into a series of categories that themselves are drawn from larger socio-cultural knowledge paradigms. So, for Rapport, it is useful to consider the "cultural" aspects of narratives, which, she clarifies, means "according to ethnic or social groupings" (39). What fails to emerge

from this insistence on a cataloguing of typologies is any analysis of illness narratives as *writing*; their contribution to both the historical record of illness and the literary canon of somatic fictions. Even where the literary appears to be the subject of analysis, as it is in the early work of Arthur Frank who sees illness narratives as situated generically as quest, restitution and chaos narratives (Frank, *Wounded*), there remains a tendency toward typology that ignores language and its specific historical valency. Of course, other scholars, particularly those whose work has been represented in publications such as the journal *Literature and Medicine*, have attended to such representations. This work, however, tends to focus on what could be called professional narratives: either the work of novelists and poets or the records of clinicians and other medically-authorized figures. There is, therefore, a gap between the sociological and the medico-literary scholarship where the illness narratives written by members of the greater social population receive no attention as narrative acts with particular historical resonance and productive literary force. Moreover, the sociological scholarship's organisation of these narratives into types is, ironically, an act of depersonalisation that reinforces rather than calls into question the "authority of the 'grand narratives' of science and medicine" that are the foundation of Foucault's claims for clinical authority (Bury 265).

There are other ways to express the situated-ness of illness narratives that do not re-inscribe either the reductive historical frame of illness as increasingly depersonalised from the late eighteenth century onwards (Jewson) or the Foucauldian paradigm of a disenchanted medicine dominated by nosological categorization and technological observation (Hydén 48). Specifically, the places and spaces that are documented within illness narratives should be read not as depictions of "environment" (Rapport 39) as though they were unmediated reports of the materiality of clinical sites but as structures of feeling that take their place within history. "Clara's Story," a narrative written in a common poetic verse form of rhyming couplets, indicates the potential relationships between a longer history and sense of place and the experience of the medical encounter. Clara writes as the daughter of an ailing mother whose condition has led to hospitalization:

Through dirty glass the morning haze reveals  
Pillgwenlly slumbering grey towards the sea  
Where giant turbines grind like drab pin-wheels  
Observed in dreadful solitude by me,  
Oppressive heat surrounds me as I hear  
The hissing of the mattress where you lie  
Wide-eyed. You watch me, helpless, full of fear.  
I know the 'Trust' will simply let you die.

This narrative expresses some of those themes familiar to scholars of illness narratives. The writer's despair, depersonalization and alienation within the medical space are clearly registered, as is the sense of helplessness when faced with severe illness. The medical staff are regarded only as part of a bureaucratic and impersonal medicine, depicted as the 'Trust', under the power of which even the writer, who thinks but does not speak, is made voiceless. It was by way of such analysis that Arthur Kleinman and Arthur Frank (*Wounded*) reintroduced illness narratives into contemporary scholarship and from which they argued for reading such narratives as authentic performances of those 'silenced' patients whom medicine had disregarded.

Yet just as vital is the geographic location of this narrative in the South Wales town of Newport, and particularly its placement in Pillgwenlly, the area of Newport that includes that town's docklands. Indeed the medical encounter is entirely contingent upon that place: it is with a view of Pillgwenlly, gained through the dirty glass with its connotations of neglect, which the poem opens rather than with an observation of the hospital ward. Although there is no explicit discussion of the history of Pillgwenlly, it is how that history relates to the medical encounter that reveals how situated this illness narrative is within a longer history and understanding of place. Pillgwenlly's "slumbering grey" connotes the former dockland industries, long departed, whose waste materials are still visible along the line of the land as it meets the Severn estuary. The industry that the poem registers is wind-farming, but the turbines secured to the sea-bed are "drab" and exist in "dreadful solitude," offshore and therefore outside Pillgwenlly's social relations. The "grind" of the wind turbines are recast, via a similar technological sonority, as the "hissing" mattress of the hospital bed, with its associations with medical technology, and this in turn also renders the "dreadful solitude" ambiguous. It might now refer not only to the turbines but also to the patient and to the writer. Similarly, within this brief but powerful urban history, the poem also draws a connection between the untrustworthy medical organisation and those other large institutions, such as the docklands industries, that cannot or could not be relied upon to provide adequate care for Pillgwenlly's communities. Indeed, the verse implies parallels of another order, too. There is continuity between the forces of industrialisation with its concomitant technologies that refashioned the landscape as an industrialised one and the effects of these same technological forces on the experience of the patient and by extension their carer. Just as industrialisation caused major disruption to the established social systems of the nineteenth century so too, the poem implies, has the technologisation of medicine disrupted normative relations between Clara and her mother.

Such an analysis may be charged with placing in dialogue two different and unrelated forms of social critique; although the fact that the poem itself does this already militates against such an argument. However, as Roy Porter and others have shown ("Patient's View", *In Sickness*; Condrau; Warner; Risse and Warner), the history of medicine cannot ignore either the perspective of the patient or the social, economic and cultural situations within which the practices and performances of healthcare and the medical encounter take place. Breaking with an approach that placed stories of progress, knowledge and breakthroughs at the centre of the history of medicine, an approach scholars in the medical humanities implicitly accept when critiquing the rise of biomedicine, the historical categories of patient, medical practice and disease were revisited and resituated to show how they were as much part of the 'social' as they were the 'medical.' Viewed from within an attentive history of medicine, "Clara's story" is an illness narrative less about the authenticity of the narrative self and more about the social conditions of illness formed over time. Interestingly, the retrospective formation of illness is also at the centre of one of the poem's key phrases: "dreadful solitude." Placing these two words together has become so common as to become cliché, but their literary history can be traced most famously to the Romantic poet John Keats, who used them in a letter to describe his experience of what was to be his final illness in Rome in 1821 (Scott). As Grant Scott has shown, Keats's posthumous reputation led several biographers to negotiate around that phrase and its suggestions of desperation that worked to undermine the cultural view of Keats as a poet of healthy philosophies. The use of this phrase in the poem, when allied to the social history that gives the narrative its focus, reveals that it is in

the combination of histories – literary, social and economic – that situates the illness narrative both within the medical encounter but also, and in ways that are crucial, extensively beyond it into networks that are unconstrained by depersonalised medicine.

A more explicit example of the importance of place within the medical encounter is “Emily’s Story”, a narrative that follows the formal structure of a diary to describe Emily’s relationships with medical institutions during her mother’s illness. At first, Emily, herself a professional nurse, professes frustration and anger at the care her mother received after suffering a stroke and being treated at a large urban hospital. While we might expect a nurse to side with medical authority, Emily tells the story of her struggles to have her mother treated, as she saw it, with appropriate professional diligence:

Mum was eventually moved to an assessment/admissions ward where we were told she would be monitored overnight. When we walked onto the unit we were greeted warmly enough. However after the handing over nurse took the accepting nurse aside there was a palpable change in the atmosphere. We both felt we were an unwanted presence. We were not welcome and it was as if our fame had spread. I found them defensive and disingenuous. Health care professionals love to label people. I’m one of them, I have done so. We describe patients and families as being difficult or demanding. Nurses only came to mum in pairs- for safety perhaps! An exaggeration I admit, but they were very cautious with us which made it very difficult to have any sort of relationship with them. This was something I had never experienced before and it was a real eye opener for me being on the other side.

Later, after her mother is discharged, but once again deteriorated, she is admitted to a smaller, rural hospital nearer to her family home:

Maybe it’s a [Welsh] Valleys thing, perhaps we share a humour that binds us and sees us through such times or maybe it was just because it’s a smaller hospital and I was known there, whatever the reason our experiences here could not have been more different. We had an easy relationship with the staff. We could laugh and chat and be consoled in equal measures. Every member of staff porters, domestics, care assistants, nurses and doctors seemed to pick up and respond to our needs and pain.

The surveillance culture, sense of disenfranchisement, and deepening understanding that Emily articulates about her own categorization as a family carer rather than as a fellow professional are all familiar generic tropes of illness narratives and speak directly to the characterization of the medical encounter as dominated by an authoritarian medical culture. At the same time, however, Emily’s opening narrative also registers what historians have argued for some time: that such authority has always been contested by patients, their families and the public who expressed doubts about medical practitioners’ claims to expert knowledge. Such doubts were voiced in early modern medical satires, in attacks on medical practices, such as dissection, in nineteenth-century protests against vaccination and vivisection, and in the growth of alternative medicine. Notions of credibility were inextricable linked to social reputation and the status of medical practitioners and their privileged understanding of

disease remained uncertain into the nineteenth century. Although efforts were made to present orthodox practitioners as Fildes's family doctor they were often imagined as vampires, butchers, rapists and murderers who fed on the bodies of the poor, anxieties that were embodied in late-Victorian Gothic literature and in speculations that Jack the Ripper was a mad doctor or medical student (Durbach; Frayling). Although Victorian medical practitioners invested in a professional rhetoric that asserted their expertise, that expertise remained subject to challenge into the twentieth century as the public used criteria different from those adopted by doctors to judge professional standing and expertise. Indeed Emily contests medical authority from one of the most common positions for resistance – expert knowledge – but frames this expert knowledge differently. Yet this narrative does not only place Emily in a long tradition of patients' struggles for their own agency. It also shows, rather uniquely, how place can significantly alter the clinical medical encounter. The second part of Emily's narrative suggests that it is both the relationships of power in the encounter with medical authority, and where that encounter takes place – rather than the nature of medical authority (as Foucault maintained) – which can either produce tensions or promote productive sets of interactions.

The ideal space of the second hospital is defined in Emily's narrative in a number of inter-related ways. There is first a sense of the local in "a Valley's thing," which gains its own credence from a communal emotional understanding amongst local people who "share a humour that binds us." It is also, though, a condition of size and familiarity, which works in two directions, both from the carer to the hospital and from the medical staff to the carer. Emily finds the "smaller" hospital more manageable, but is also relieved by the fact not that she knows the medical staff, but that they know her. These examples of a "banal" nationalism (Billig), here articulated as localism, radically redefine the medical encounter, entirely excising medical authority in its Foucauldian sense. It is replaced by a sense of belonging that is almost utopian: "Every member of staff porters, domestics, care assistants, nurses and doctors seemed to pick up and respond to our needs and pain." This is clearly set against (and indeed gains some of its heightened emotional intensity from) the uncanny urban hospital of the first part of the narrative.<sup>3</sup> The structure of the narrative – its movement from the entirely clinical space of the first hospital to the social and cultural familiarity of the second – also interestingly parallels the evolving historiography of hospitals and their functions or meanings. Since the 1980s and especially in the early twenty first century, historians have revised their view of the hospital as place responding only to advances in medicine to take account of the hospital also as a social and political space (Granshaw and Porter; Henderson et al.; Waddington 144-65). By placing the wider socioeconomic and political contexts at the centre of hospital history, historians revealed how there was more to the hospital than medical encounters, medicalization, or ideas of social control. As the hospital increasingly came to be viewed as "a microcosm of society," they emerged as important local institutions that were embedded in local networks of support and medical care (Granshaw and Porter 4). Close associations developed between hospitals and the communities they served. New types of institution, such as the cottage hospital, emerged in the second half of the nineteenth century to meet local medical needs (Cherry), but even general hospitals remained firmly embedded in their locality in the early twentieth century. Emily's narrative therefore not only offers a specific instance of a form of medical contestation noted by historians but also provides a unique example of the kinds of evidence that support new revisionist histories of hospital culture.



### **Aesthetic Epistemology**

One further context into which Emily's narrative may be placed, and which sociological studies of illness narratives have emphasised, is the "collective experience" (Hydén 59) of patients and their support network (Zola; Viney and Bousfield). This scholarship regards illness not as an individual experience but rather as located within social contexts or communities, a view that echoes debates among historians of medicine about how experiences of disease are socially constructed (Jordanova; Harley). Certainly Emily's narration of the local hospital appears a good example of such communitarian medicine and the social embeddedness of medical narratives. While this is undoubtedly valuable in enabling sociologists to understand how identities are created and maintained in the struggle against illnesses that can be effacing it fails to take account, once again, of the writing itself. Studies of social context from this perspective tend to read illness narratives as matters of fact, or at least of biographical truth; as "life histories" (Hydén 59) that draw the narratives out of the private sphere (the authentic individual self-experience) and into the realm of useful social or empirical data. There is a utilitarian sensibility to employing illness narratives in this way (where narratives are interrogated for their accomplishments and broader relevance) that ignores their aesthetic achievements as well as the new knowledge that an aesthetic epistemology can offer. For example, Emily's choice of vocabulary in describing her experience in a large urban hospital, rather than the facts of her narrative, reveals how the medical environment had become spectral. She notes the "atmosphere," her "unwanted presence" and how ultimately she felt "on the other side." This growing sense of herself as ghost-like draws on gothic tropes to articulate a corporeal, emotional knowledge of her own disempowerment. Such understanding is essentially aesthetic; once again in its original meaning as a discourse of the body that comes to reason through a materiality and psychology of feeling, allowing us to bridge the conceptual gap between the operation of social or cultural 'discourses,' and the bodies and subjectivities of individuals.

"Charlotte's Story," the narrative of a medical encounter of a family member with the clinical spaces used to treat kidney patients, provides an even more acute gothic aesthetic:

As we entered the ward I'm sure that my face must have betrayed all that I felt inside. I could barely breathe; such was the level of emotion and anxiety I was experiencing. The room was filled with beds, each inhabited by a very sick looking person who was hooked up to a large, ugly machine. There was a constant low level hum and my strongest visual memory is of blood. Blood being pumped through tubes, out of arms, into machines and back again. And sad yellow faces, out of which stared dull, lifeless eyes.

Charlotte's response to the clinic is a directly aesthetic one: she feels the experience in and through her body. Despite the fact that the narrative claims to be a "visual memory" its textual and textural complexity cannot fully be realised by reading it within the observational paradigms of Foucauldian medical discourse which negotiates the terrain of the objective and subjective clinical experience. As Meegan Kennedy highlights, even mid-nineteenth century clinical case histories were never just about the objective or subjective experience but shared the "romantic discourse of the Gothic" ("The Ghost" 327). Just as the nineteenth century clinical case history was both a historical and literary construct, "Charlotte's Story" must be recognised as one already filled with literary and historical knowledge and specifically with a gothic

mythology of the pathological body. This is to read the narrative entirely against the grain of certain scholarly perceptions of illness narratives. Arthur Bochner, writing in response to Paul Atkinson's call for objective approaches to narrative data, argues that the work of analyzing narratives is entirely subjective: "When I sit down to analyse a story, there's the story, and there's me. The meaning of the story is not immanent in the text" (135). Yet in Charlotte's narrative the meaning is entirely encapsulated within the text itself and how that text suggests its relationships to other texts, especially popular myths.<sup>4</sup> Meaning emerges not in the relation between text and critic but in the text's richness and 'originality' – its seeking out of pre-existing origins in other textual forms.

Although it is implied rather than revealed, the aesthetic discourse of Charlotte's narrative links history with myth-making fiction to construct a vision of disease and its sufferers as monstrous. For instance, Charlotte's bodily experience of the dialysis ward leads her to an aesthetic that focuses on blood. This initial 'visual' and visceral stimulus parallels the moment in Bram Stoker's gothic novel, *Dracula*, where the narrator sees the monstrous vampire for the first time:

And then I saw something which filled my very soul with horror. There lay the Count, but looking as if his youth had been half restored. For the white hair and moustache were changed to dark iron-grey. The cheeks were fuller, and the white skin seemed ruby-red underneath. The mouth was redder than ever, for on the lips were gouts of fresh blood, which trickled from the corners of the mouth and ran down over the chin and neck. Even the deep, burning eyes seemed set amongst swollen flesh, for the lids and pouches underneath were bloated. It seemed as if the whole awful creature were simply gorged with blood. (51)

There is more to the parallel between Charlotte's narrative and Stoker's influential vampire myth than the repetition of blood. Like Stoker's narrator, Charlotte is encountering the monstrous effects of transgressive blood circulation for the first time. And also like Stoker's narrator Charlotte is confronted by the possibility of bodily transformation and its monstrous effects, which resonate with late Victorian Gothic concerns about the instability of the body (Halberstam; Hurley). Later in her narrative, she asks herself "Was it really possible that he would soon be yellow and sad like them?" The yellowing effect on the skin of kidney disease is not only referred to in this question but also prior to that, in the "sad yellow faces, out of which stared dull, lifeless eyes." This image, too, has its intertextual referent. In particular it is reminiscent of another gothic narrative of monstrosity, Mary Shelley's novel *Frankenstein*. Shelley's description of the monstrous creature created by Victor Frankenstein's new science tells us that:

His yellow skin scarcely covered the work of muscles and arteries beneath; his hair was of a lustrous black, and flowing; his teeth of pearly whiteness; but these luxuriances only formed a more horrid contrast with his watery eyes, that seemed almost of the same colour as the dun-white sockets in which they were set. (56)

Frankenstein's remembrance of the yellow skin and the eyes, which frame his description, is markedly similar to Charlotte's memory of the dialysis patients, who

are themselves the same complex combination of humanity and artificiality that marks out Victor Frankenstein's creature as monstrous.

The intertextual aesthetic parallels with *Dracula* and *Frankenstein* reveal how far Charlotte's own narrative is one of monstrosity; the horror of being identified as monstrous, and the fear of becoming the monster. Nowhere does her narrative explain this, or make explicit those concerns, but the effects on her body (as she narrates them) clearly indicate that it is within a longer fictional mythology that such ideas take root and through which they become expressed to reveal the shared narrative and aesthetic arena between illness narrative and the gothic. Charlotte's narrative can therefore be viewed as part of a historical tradition in which disease is characterised as monstrous and an invader (Gilman; Hardy; Healey; Lindemann; Sontag). This depiction of disease can be found, for example, in early modern ideas about monstrous births, eighteenth century representations of gout, Victorian discussions of cholera or physical deformity, or contemporary impressions of cancer. The historical scholarship on disease representation stresses that identifying disease as monstrous is a way of understanding the social and personal implications of illness and its effects on individual identity (Deutsch; Durbach). The use of imaginative metaphors of monstrosity is a way of making disease comprehensible and to understand its relations to the self and others. Charlotte's imaginative investments perform this role in her narrative; but additionally they connect her experience to similar historical experiences. Her story, then, is not inscribed within the boundaries of clinical experience or under the power of the medical gaze but instead extends far beyond her particular medical encounter by placing her story in an imaginative community within history and fiction.

For Bochner, Charlotte's story would have none of these important associations, for the text itself would offer nothing of value beyond its access to the storyteller as an authentic individual or the scholar as an analyst of that individual (and of his/her own practice in analysis): "The process of theorizing, analyzing, and categorizing personal narratives is shot through and through with the imagination and ways of seeing of the interpreter" (136). While Bochner's point here is to stress the importance of observer reflexivity, in direct opposition to the scientific objectivity proposed by Atkinson, it also indicates a particularly Foucauldian relation between the scholarly analyst and the illness narrative and its writer. Bochner's claim that meaning must be imposed upon an illness text by the reader tends towards the same relationship of power that Foucault identified as the medical gaze. That is, it is the observer who has control and authority while the text or patient is silenced. Despite Bochner's championing of the authentic illness writer and his (admirable) quest to see their narratives as meaningful, his methodological stance undermines that project by adhering to a structure of relations that replicate the clinical encounter he is writing against.

Even illness narratives that are written from within the most tightly controlled form of the medical encounter still produce text that has the kind of imaginary investment that produces connections to its literary and historical predecessors and thereby allow it to accrue meaning beyond the gaze. Medical and psychiatric case notes are notoriously restrictive in their form and content, offering mainly "therapeutic instructions" and serving to reinforce the "representational ideals" of the depersonalised medicine that emerged in the second half of the nineteenth century (Andrews; Warner n.p.). One set of case notes from 1912, held in the Bethlem Royal Hospital Archive, details the final year of a patient called Abraham Raphael who had been admitted with "dementia of the general paralytic" (1).<sup>5</sup> Raphael's case is typical:

"patients with GPI were admitted to countless private and public asylums during the period and Raphael is just one such example" (Waddington, "General Paralysis" 367). Yet within the case notes recorded by Raphael's attending physicians there is, as with Charlotte's story, a bodily aesthetic that emerges as belonging very clearly to Raphael himself. While the majority of the notes present a medicalised account of Raphael's deteriorating condition (marked by medical language and the standard physician's shorthand) his own voice is also given narrative purchase, even if this is supposed only to exemplify the increasingly debilitating dementia from which he suffers.

Emerging from Raphael's discussions with his physicians, probably best described as reported monologues, is first his religious affiliation to Judaism. He describes himself as "the chosen of God" and a "perfect man" (3). He also related a series of extraordinary stories which feature mathematics (his former professional role was as a school headmaster): these include his claims to have drunk "1,000,000 bottles of wine" in an Italian café, and to have bought "more than 1,000 eggs for his schoolchildren" (3). The notes also include (as inserts) scraps of paper on which Raphael has attempted unsuccessfully to complete multiplication sums (5). Unlike the reported monologues these sums are diagnostic tools for Raphael's physicians which, they believe, indicate his increasing dementia. Although there is no indication in the case notes of the meaning of Raphael's incongruous comments they are clearly connected to the sums: they are reported, it is reasonable to assume, in order to register his growing mental derangement. To consider these from Raphael's perspective is clearly more difficult. The narratives are provided by his physicians, after all, even if the sums are his own. Yet it does appear that his mathematical fantasies are efforts to claim some kind of control over his own bodily and mental deficiencies. His narratives, even second-hand, are at least partly somatic fictions designed to offer some kind of resistance to the self-recognised deterioration of his condition. To that extent, Raphael's reported narratives work in parallel to Charlotte's contemporary story; they, too, are aesthetic responses emerging out of a bodily disruption that provides Raphael with a particular construction of self-knowledge as mediated through his disease. Rather than regarding these reported narratives only from within the perspective that authorised medicine placed on them, they might be read as imaginary investments in a myth of mathematical order that Raphael employs to counter the pathological schema of his dementia.

However, a more powerful historical myth also invades Raphael's narratives: the myth of the perpetrator of the Whitechapel Murders of 1888, who had been given the name Jack the Ripper. Following from his discussion of his Jewish religion, Raphael, his physicians report, "says that he has prevented a great many unmarried women from becoming pregnant by passing a lancet and an electric lamp up the rectum and then removing the uterus, ovaries and fallopian tubes, this is also apparently to prevent them suffering from syphilis" (3). As many social and cultural historians have shown the modern mythology of the Whitechapel murderer was already being constructed even as the murders continued across the later months of 1888 (Curtis; Frayling; Oldridge). Central to that mythology both at the time, and in the 1910s when Raphael was being cared for at Bethlem, was the relationship between the murders, the murderer and medicine, and in particular to a style of medicine associated with physiology and the laboratory, seen as essential components in the emergence of modern biomedicine. The murders were thought to be horrific transgressions of medical practices in their hideous desecration of the female body and its reproductive system (Walkowitz). The murderer, it was speculated, may have been a man with medical knowledge and training, perhaps even a practising

physician, surgeon or a "physiologist delirious with cruelty" (Power Cobbe). Indeed the name given to the unknown perpetrator, Jack the Ripper, encapsulated that understanding of the close relation between medicine and the murders by using a common term for the ancient practice of anatomical dissection (to rip). One other key feature of the Whitechapel murders was the suspicion that fell on those communities in the area regarded as non-British, and in particular the East End's Jews.

Raphael's narrative of invasion of the female body clearly resonates with the Whitechapel Murders in several ways. First, Raphael's status as London Jew allied him with those who came under intense scrutiny in 1888. Second, his fantasised violence against female reproduction, and its associations with aberrant sexuality leading to sexually-transmitted disease, repeats the activities of the Whitechapel murderer. Yet his narrative is also more complex than this. By narrating a clearly fictional version of himself as a latter-day Jack the Ripper, Raphael is associating himself both with the medical profession and the sexual psychopath who may have committed the crimes. The reason for the latter association is self-evident: Raphael is himself suffering from syphilitic dementia that has already undermined his mental stability. He presents this, from a patient's fearful perspective, within the condition of an historical myth that stresses the gothic horror of such suffering as well as the gothic associations with the institution (Bedlam) in which he found himself. At the same time his present medical encounter colours his relationship with the attending physicians, and he incorporates into his myth-making fiction a view of their clinical investigations of his illness made equally horrific and transgressive. Indeed what Raphael's historical analogy with the Whitechapel murderer achieves here is to offer an extreme critique of the depersonalised medical gaze by making that gaze monstrous and destructive, reinforcing the idea that the patient must be conceptualised as an integral part of biomedicine (Armstrong; Warner 1999).<sup>6</sup> More radical, however, is Raphael's association of his own position with the female victims of the Whitechapel murders. It is, after all, he and they, in his narrative, who are potential victims of both syphilis and medical intervention (horrifically perceived as that is). What this allows Raphael to register is both a fantasy of good health and recognition of the horror of illness. His re-enactment of Jack the Ripper is a mode of prevention in which the women (and he) are saved from the dangers of syphilis. Yet to imagine the women (and himself) as victims of Jack the Ripper is to acknowledge, too, his own destruction. To read Raphael's fantastic narratives in the case notes from an historically-informed perspective is to gain access to his self-understanding of his condition in ways not otherwise possible. His Jack the Ripper narrative is an aesthetic enactment that comes to knowledge through collaboration with a myth-making history that exists beyond the medical encounter. To limit the narrative either to clinical concerns, or to presentist readings of the patient within the moments of the clinical experience, would be to deny it that knowledge.

### **Re-enchanting Narrative Medicine**

One of the key concerns of scholarly work on illness narratives has been to retrieve the wonder of the patient perspective from the depersonalizing clinical voice. This has been articulated – via Max Weber's influential reading of the effects of twentieth century science – as an effort to re-enchant patient narratives (Weber). Frank, in particular in his 2002 essay on the study of stories, argues that patient narratives are "acts of reenchantment" (110) while Warner more recently claimed that greater attention to both writing and observational practices in the study of case notes provides an opportunity to "re-enchant the art of healing" (n.p.). For these writers re-

enchantment is implicitly a response to the disenchantment brought about by bureaucratic and professional discourses within medicine, of the type that Foucault employs as further evidence of the emergence of a domineering clinical gaze. To re-enchant, therefore, is to reclaim the aesthetic and imaginative qualities from a system that reduces illness narratives (and healthcare more broadly) to nothing more than a further set of utterances that provide specialist medical data. Both Frank and Warner are right to promote the potential for enchantment that exists within narratives of illness. Nevertheless, their method for achieving a form of re-enchantment is implicitly to accept Foucault's construction of the medical encounter and seek out methods of study that might manage to construct some sense of struggles against it. For both scholars this necessitates a promotion of the individual; the individual observer and the observed subject for Warner and "the authenticity of the personal" narrator for Frank (116). There is, however, another way to approach the enchantment of the narratives produced around illness and the clinical medical encounter, and that is, as this article has shown, to reject Foucault's paradigmatic insistence on the totality of the medical gaze and reveal that the enchantments and "imaginary investments" have always been there in the narratives themselves.

This is undoubtedly a reversal of much that has been written of illness narratives. In particular it demands thinking about narratives in a way that disrupts their very existence as narrative forms; a disregarding of their linear temporality, their cohesion of the self or selves, and their sense of progress towards greater individual truth or understanding. The narratives discussed in this article have not been read as narratives but rather as episodes – independent aesthetic moments given life in language – in whose interstices other episodes of historical and literary significance have been revitalised and given new meaning. There is, after all, no reason to accept that lives are lived only as narratives: a point that the philosopher Galen Strawson makes very persuasively. For Strawson "it's just not true that there is only one good way for human beings to experience their being in time. There are deeply non-Narrative people and there are good ways to live that are deeply non-Narrative" (429). Indeed, for Strawson narrativity "close[s] down important avenues of thought" (429) and the tendency to seek for individual identity in narrative cohesion is "a gross hindrance to self-understanding" (447). In the same ways as Strawson, if not articulated quite so starkly, revisionist historians of medicine find cohesive and progressive understandings of the past suspicious as they seek to problematise the nature of medicalization and shake off the idea that modern biomedicine is essentially correct. Likewise, in a literary context, Catherine Belling has called for greater attention to the lyricism in fictions of medicine rather than their identifiably narrative experiences (2-6).

Illness writing – whether in official medical case notes or in fictional and non-fictional patient stories – can be investigated as an individual instance of the imagination that connects the clinical encounter to history and to fiction. Illness narratives read in this way take us past the patient (authentic or otherwise) and beyond the traditional boundaries of the medical encounter by investing in a different kind of textual community where historical artefacts, mythologies and fictional representations meet. This association is as vital a form of authority for the patient or their family member as the on-going project to give credence to their stories through the promotion of their moral authenticity. Indeed this textual community of history and fiction reveals that the "unnatural act of violence against the body" (Harland 103) that Foucauldian paradigms continue to circulate as the truth of medical encounters is

not its totality. There remains far more that does, and always has invested in the powerful enchantments of other stories, historical and fictional, myth and imagination.

## Notes

1. Martin Willis is principal author, Keir Waddington co-author and Richard Marsden corresponding author.

2. This narrative, entitled "Marie's Story", along with others to follow throughout the article, was produced for the Off Sick Project, a collaborative research initiative investigating contemporary illness narratives related to the medical encounter. The narratives were entirely self-generated, sometimes with the support of a creative writing workshop, and sometimes without. The participants were given no specific criteria for their narratives other than to consider their experience of the medical encounter, as they perceived that. The project was funded by the Universities of Glamorgan and Cardiff and led by the authors. All the participants in the project agreed for their narratives to be used in research publications. All names have been altered to provide anonymity to the writers. The project's work, and the complete narratives, can be viewed at [www.officksproject.co.uk](http://www.officksproject.co.uk). Unless otherwise specified all the narratives presented in the article are drawn from this project.

3. A similarly uncanny experience can be found in the published illness narrative of Welsh poet, Gwyneth Lewis. In *A Hospital Odyssey*, a contemporary pastiche of Homer, Lewis depicts a large urban hospital as a vast and unknown landscape which must be traversed in order to reach the safety of home.

4. In discussions with Charlotte based on the analysis of her narrative presented here she avowed no explicit intention to alert readers to the inter-texts that we identify, nor indeed any intention on her part to draw from those narratives in constructing her own. The meanings that therefore emerge in this analysis do not do so from any authorial position.

5. Raphael's general paralysis of the insane (GPI) or paralytic dementia occurred as a result of his having contracted syphilis. He was admitted to Bethlem on 11 Feb 1910 and died there on 25 Dec 1912. The authors would like to thank the Bethlem Art and History Collections Trust for permission to quote from the Male "Case Notes" and Colin Gale at the Bethlem Royal Hospital Archive and Museum Services for his help and support in making them available for research purposes.

6. If the medical gaze actually performed in the powerful way Foucault describes then Raphael's narrative would not exist in the case notes to the extent that it allows for this interpretation to be brought out. The very existence of the critique of the medical gaze fundamentally undermines the position it is presumed to hold.



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