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"The Graphic Proximity of Intimate Loss": the Role of Narrative Medicine in Articulating Marginalised and Excluded Voices

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Academics apply value judgments on the legitimacy of Narrative Medicine and whether it actually evokes an untapped empathy in medical professionals. However, by adopting a purely educational perspective, academics exclude the voices of the sick/dying who exist beyond institutional walls. In Section I, this paper unpacks the opposing views surrounding the successes and limitations of Narrative Medicine but ultimately moves to understand the ways in which it seeks to reach the otherwise excluded voices of the sick/dying. This paper then adopts Eve Kosofsky Sedgwick's White Glasses (1991) as a case study, in Section II, to further probe the ways in which Narrative Medicine can embrace diversity and interrogate the subjectivity of Narrative. However, whilst an individual narrative such as Kosofsky Sedgwick's offers insight into a singular lived experience of suffering, Narrative Medicine as a genre excludes many voices when it disregards those with an inability to describe their lives narratologically. So, in Section III, this paper explores the potentiality for a more all-encompassing interpretation of Narrative Medicine which holds space for more diverse representations of suffering. Through the analysis of Frida Kahlo's What the Water Gave Me (1938) this paper argues that by embracing pictorial representations of human experience, Narrative Medicine can evolve into more inclusive space. The role of Narrative Medicine in the Medical Humanities remains mobile but, despite its limitations, a personalised approach to pathography articulates the marginalised voices of the sick/dying.

When Stephen Pattison outlined his ambition for the field of Medical Humanities in 2003, he wrote that:

> The Medical Humanities movement would prize diversity of forms. It would affirm, stimulate and develop all those who are likely to be affected by it (potentially anyone who might be a patient or carer) and to be maximally inclusive. It should aspire to be a 'broad church' of many languages and kinds of performance and analysis in which bridges are built and conversations occur that reveal things to participants that they could not have learned within their own original limits and worldviews (33).

And yet, almost two decades later, the "diversity of forms" presented in Narrative Medicine remains a point of contention within the Medical Humanities' literature. Academics, such as

John Gillies and Charlotte Blease, apply value judgments on the legitimacy of Narrative Medicine and whether it actually evokes an untapped empathy in medical professionals. By following this line of argument, academics fail to address the full range of “conversations” engaged with by the sick/dying beyond institutional walls. In Section I of this article, I unpack the opposing views surrounding the successes and limitations of Narrative Medicine, ultimately moving to understand the ways in which it “builds bridges” over the chasms of misunderstanding to reach the otherwise excluded voices of the sick/dying. Then, in Section II, using Eve Kosofsky Sedgwick’s 1991 essay *White Glasses* as a case study, I will probe the ways in which Narrative Medicine can “prize diversity” and interrogate the subjectivity of narrative. However, whilst an individual narrative such as Sedgwick’s offers insight into a singular lived experience of suffering, not all people can articulate their lived experience in linear, diachronic terms. Narrative Medicine, as a genre, risks locking the doors to its “broad church” if it disregards those with an inability to articulate their lives narratologically. In Section III, I will explore the potentiality for a more all-encompassing interpretation of Narrative Medicine which holds space for more diverse representations of suffering. Through the analysis of Frida Kahlo’s *What the Water Gave Me,* created in 1938, I argue that by embracing pictorial representations of human experience, Narrative Medicine can evolve into the “maximally inclusive” space Pattison envisioned. The role of Narrative Medicine in the Medical Humanities remains mobile but, despite its limitations, the personalised approach to pathography articulates the marginalised voices of the sick/dying.

Narrative Medicine

A reductionist biomedical model of disease demarcates a person’s identity within the parameters of their medical diagnoses. Clinical notes and diagnostic scans substitute for the total bodymind of the suffering individual. Such medicalised documents disregard a person’s history, relationships, lived experiences, and compress the patient down to an anatomical model. As Arthur W. Frank argues in ‘Being a Good Story: The Humanities as Therapeutic Practice’ (2014): “the medical history is not the ill person’s story”; their physiological form is but a fraction of their selfhood (15). When the role of patient dominates the discourse, “ill people forget that their lives are more than being sick” (15). So, by constructing a Narrative Medicine, the patient metamorphoses back into a state of personhood.

Doctors seek to circumvent the voices of the sick, according to Frank, and in response, Frank weaponizes Narrative Medicine to undermine this paternalistic approach and recentre the story of the person. Whether, as Rita Charon advocates in *Narrative Medicine: Honoring the Stories of Illness* (2006), it is to "protect themselves from the sadness of taking care of very sick people or to guarantee the objectivity of their clinical judgment," medical professionals remain at a remove from those they treat and become victims of the sterility of their profession (6). Narrative Medicine therefore refocuses the discussion on the 'very sick people' and seeks a more holistic understanding of the humans present in the doctor's office.

Even with Medical Humanities featuring in the medical curriculum, doubt remains as to whether Narrative Medicine can realistically induce empathy and altruism in medical professionals. After all, Charon concedes that such traits must be "developed and nurtured from infancy onward" (8). If this is true and Narrative Medicine does not actually "affirm, stimulate and develop all those" who study it – as Pattison hoped – then one might query its purpose entirely (33). However, to assume that the Medical Humanities' primary function is to provide assistance to its clinical counterparts is to treat the field as the "supportive friend" of a more dominant subject rather than a legitimate study in its own right (Brody 2). Instead, Narrative Medicine, explored for its own sake, allows the therapeutic sharing of trauma and processing of experience. I would not go as far as Jane McNaughton in positioning the Medical Humanities as "a disruptive teenager" but would support a state of symbiosis to create a collaborative field of study with Medicine (McNaughton 927). Therefore, whilst Narrative Medicine may not induce a paradigm shift amongst the most apathetic medical students, it creates a space wherein Pattison's "bridges are built" and a multiplicity of voices emerge to challenge the "original limits and worldviews" of the able-bodied onlooker (33).

Furthermore, Narrative Medicine deconstructs the concept of a monolithic sick experience. Angela Woods, in 'The Limits of Narrative' (2011), describes narrative as "the primary vehicle through which the ill person can express her changing sense of self and identity, explore new social roles and gain membership of new communities" (73). By this reasoning, not only are narratives formulated within the constraints of identity, but they also create new identities through their own conception: when the author of a pathography explores their sense of self they are simultaneously recording their experience in a disabled body and moulding new spaces for their intersecting identities.

Although able-bodied and healthy authors continue to adopt the perspective of the sick/dying it is only through misfortune and necessity that a truly autobiographical pathography comes to fruition. This means that there inevitably exists an absence of certain marginalised voices who remain unable or unwilling to divulge their trauma and an overabundance of those expressing their lived experience from positions of authority. Frank argues: "the humanities have extraordinary resources that can help ill people first to tell good stories and then in the telling to *become* good stories" (14). However, this unification of aesthetics and health disregards the experiences of those who do not assimilate into the healing journey narrative. 'Being a Good Story' strives to re-present illness as "something worth living with" by displacing the clinical anonymity of medicalised documentation (Frank 13). However, it positions narrative competence above the individuality of suffering and so inadvertently silences the lived experiences of those without the capacity to construct a fluent and coherent story. Ultimately, Narrative Medicine must embrace a dynamic plurality of voices if it is to navigate the complexities of conflicting realities and the legitimate representation of an inherently subjective experience.

***White Glasses*: A Case Study**

One way in which the Medical Humanities empower the deconstruction of a reductionist medical model and dismantle a hierarchy of experience is by platforming narratives constructed by marginalised voices. Consider Sedgwick's *White Glasses*. The text does not seek to reconcile the differing lived experiences of its subjects but rather it creates space for multiple identities.

White Glasses straddles both personal experience and appropriated suffering of Narrative Medicine; whilst the text affords access to Sedgwick's own life with cancer it also wrestles with the vicarious experiences of Bill and Michael's HIV diagnoses. Sedgwick acknowledges that sharing "the same loss, the same history of struggle and subtraction made Michael available to my identification and love", but she also admits that he remains "opaque to my knowledge" as she navigates the problem of speaking for the Other (194). Sedgwick identifies the challenge as the "graphic proximity of intimate loss" setting the text up to grapple with its role as both autobiography and second-hand recall of Narrative Medicine (194). The double meaning of "graphic" as both "pertaining to writing" and being "vividly descriptive, life-like" (OED) underscores a fractious relationship between the physical intimacy of holding the textual product of *White Glasses* and the reader's psychological removal from Bill's suffering. Despite increasing the proximity of the healthy and sick through the discussion of Bill's life, Sedgwick acknowledges the inherent boundaries present between passive observer and Bill's lived experience.

By avoiding the tropes of speculative pathography Sedgwick solicits empathy for the dying Bill. Rather than indulge in the gratuitous presentation of physical decay that she herself did not witness, she instead repeats the clinical and anaesthetic phrase "Bill's diagnosis" and in lieu of a list of medicalised symptoms associated with his "complicated, arbitrary, diagnosis", Sedgwick adopts descriptors orientated around a compassioned identity (194). *White Glasses* describes Bill in terms of his relationships with others. He is "Michael's ex-lover, housemate, best loved-friend, a medical researcher, Bill Lewis," so that his identity extends beyond the confines of his diseased corporeality and instead establishes him within a sphere of physical connections (194). The juxtaposition of anaesthetic medicalisation and emotional connection forces the character to oscillate between removed clinical subject and individual human, who – although segregated from healthy society and textually out of reach – shares the familial and social relations that counteract the anonymity of disease. Sedgwick's narrative account acknowledges its inability to resolve the disjoint between lived experience and observer but nevertheless conjures a more intimate connection that seeks to bridge the alleged dichotomy of the living and dying.

The artificial binarism established around living and dying in *White Glasses* questions the unreliable subjectivity of the narrator in a Narrative Medicine. Angela Woods writes in 'The Limits of Narrative' (2011) that "a person's narrative or story, however defined, is assumed to be coextensive with their subjective experience, their psychological health and indeed their very humanity" and, as a result, this cultivates a space for not only self-empowerment but self-deception within the form as demonstrated within *White Glasses* (73). Sedgwick wrestles with the assumptions constructed within her own narrative when she writes:

> I formed my identity as the prospective writer for speaking, the margin of my survival and exemption, was the clearest thing in the world. In fact it was totally opaque: Michael didn't die; I wasn't healthy: within the space of a couple of weeks, we were dealing with a breath-taking revival of Michael's energy, alertness and appetite - also with my unexpected diagnosis with a breast cancer already metastasised to several lymph nodes. So I got everything wrong (196).

Returning to the word "opaque" Sedgwick acknowledges the self-delusion of the seemingly healthy individual who relegates the sick to a category of Other. An imaginary impenetrable barrier which protects the living from the dying within her mind, but one rapidly dismantled with the realisation of her own cancer diagnosis. Whether due to internalised ableism; confusion resulting from medication or disease; denial or merely a lack of medical understanding, the narrator in pathography presents a problematic subjectivity within the genre. Narrative Medicine enters a blurred space of self-expression potentially riddled with (un)conscious self-deception and biases. *White Glasses* consequently represents a genre that requires a reflection *upon* rather than a reflection *of* reality.

Through this self-reflection, the text positions itself to broach the biosocial complexities of HIV/AIDS in a way inaccessible to medical texts. Charon acknowledges that:

> As medicine has had to round up on itself defensively, it is less equipped to initiate honest and consequential dialogue with the public about such grave issues as equity in healthcare, the limits of medical power, and the ideals of health care envisioned – and invested in – by this country (7).

So, although clinical records report that by the end of 1990 8-10 million people were thought to have HIV/AIDS worldwide (with 307,000 AIDS cases officially reported to the U.S. Department of Health) it is only through the lived experiences of those with intimate proximity to the AIDS epidemic that the human cost surfaces (Chin 277-283). Narrative Medicine thus bears the weight of medicine's defensive silence. For example, Sedgwick writes that "Michael was supported by amazing resources of affection, information, and the most mundane personal care from the communities he has himself created" (195). By penetrating this superficially uplifting statement of camaraderie the text acknowledges the neglect suffered by ostracised AIDS patients. According to Vanessa Vieities, fear of contracting HIV led medical professionals to leave "food trays to pile up in hallways outside AIDS patients' rooms and [nurses] left those suffering from disease to sit in soiled sheets" so that they became dependent upon other members of their community to assist them in their vulnerable state (para. 3). Descriptions of inequitable healthcare and the social stigma around the so called "gay cancer" puncture the Narrative Medicine of *White Glasses* so that the diseased body sits within a complex framework of social ills carefully elided from medical documentation (para. 3).

Michael's "opaque" body therefore performs as a microcosm for the fragmented understanding of AIDS itself (194). As Paula Treichler identifies in 'AIDS, Homophobia, and

Biomedical Discourse: An Epidemic of Signification', AIDS "is simultaneously an epidemic of transmissible lethal disease and an epidemic of meanings or signification" (265). Within a medical setting, labelling Michael's disease enables a pathway for medical treatment, but in a broader social context it also erects a stigmatisation around his diseased form. The "flaming signifier" of the eponymous white glasses when adorned on the body of a homosexual man (as opposed to the female form of Sedgwick) identifies him as gay and by proxy, a threat (194). When applied to gendered bodies the glasses perform as Butleresque indicators of a marginalised sexuality. The OED describes the slang usage of "flaming" as "designating a man whose homosexuality is conspicuous or apparent, esp. because of his flamboyant or effeminate mannerisms or clothing". The glasses do not solely serve a medical function by providing sight, but they adopt a pseudo-scientific role demarcating him as contagious. Whilst Sedgwick's wry reclamation of the derogatory adjective transforms the glasses into proud signifiers of Michael's identity their significant weight takes on the added responsibility of representing the mythology around the AIDS epidemic and the inequity of suffering associated with it.

Sedgwick's construction of narrative stems from the social and biopolitical framework from within which she wrote, but thirty years later, the reception of *White Glasses* continues to evolve as the societal relationship with HIV/AIDS shifts. Initially performed in 1991 at the 'CUNY Centre for Lesbian and Gay Studies Conference' in New York, *White Glasses* came to fruition at the same time as the Visual AIDS Artist Caucus developed the 'Red Ribbon Project' in a bid to deconstruct what Sedgwick described as the "homophobic discourse" which engulfed the discussion around the virus at this time (194). Since then, medical advancements mean that the inevitably fatal "gay man" disease of the 1980/90s no longer guarantees a death sentence so it can no longer be assumed that a reader of *White Glasses* has first-hand experience of AIDS-related death (193). With the development of Highly Active Antiretroviral Therapy (HAART) reducing the viral load to "undetectable" levels within six months of commencing treatment, many people are able to lead long and relatively healthy lives whilst living with HIV[1]. In some ways, the text offers a historicised insight into the homophobic narrative of the disease.

However, the individual experiences of the HIV positive population remain complicated by inequitable access to healthcare (predominantly directed by racial, geographical and

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[1] According to information released on the NHS website. NHS, 'Treatment', *HIV and AIDS* accessed 31 October 2021,
https://www.nhs.uk/conditions/hiv-and-aids/treatment/.

socioeconomic divisions) so that for certain marginalised identities, the risk of AIDS remains immediate and visceral[2]. Consequently, the description of "the grogginess, discontinuous attention, extreme weakness, futile attempts to regain weight and alertness" described by Sedgwick segregates a twenty-first century readership not by their inclusion within, or separation from, the queer community but along the more complex and intersecting lines of those with access to medication and those without (195). Although navigating away from a homophobic framing, the disproportionate effect of HIV on certain communities alters the immediacy of Sedgwick's narrative and so the text continues to create space for the "honest and consequential dialogue" missing from the contained and defensive clinical texts (Charon 7).

Pictographic Narrative Medicine

Despite Narrative Medicine's evolution as an intersectional countermeasure to the healthcare system's detachment, the genre continues to exclude certain marginalised identities by presuming a psychological narrative thesis. Western society's inclination to prioritise the written word over other art forms leads to an ableist and elitist omission of certain pathographies. In 'The Limits of Narrative', Woods writes against the amalgamation of a written Narrative Medicine with other creative forms (such as painting, poetry, and dance). She fears that "overinflating what counts as narrative" risks "mistaking a specific form of primarily linguistic expression for the master-trope of subjective experience" (74). However, if this "overinflation" cannot occur, for the sake of the semantic preservation of "narrative", a whole population will be rendered mute in the presentation of their own stories.

Instead, by incorporating pictorial representations – such as Kahlo's *What the Water Gave Me* (fig.1) – into the genre of Narrative Medicine, a space emerges within which to interrogate the individual suffering of a broader community. Psychologist Jerome Bruner writes in *Making Stories: Law, Literature, Life* (2002) that "it is through narrative that we create and re-create selfhood […and that] if we lacked capacity to make stories about ourselves there would be no such thing as selfhood" (85-86). This approach to identity prioritises an ableist and neurotypical view of self-expression. I would argue that Kahlo's *What the Water Gave Me* explores the idea

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[2] For more information on racial, geographical and socioeconomic divisions surrounding HIV/AIDs see (Marmot).

of selfhood whilst simultaneously disregarding the conventions of Bruner's philosophy. Despite a non-linear manifestation of a life of chronic pain and trauma, the oil on canvas piece embodies Kahlo's lived experience. *What the Water Gave Me* adopts what Andrea Kettenham calls Kahlo's "own highly personal pictorial language" drawing on at least twelve previous works to form an assemblage of lived experience (48). Unlike the centralised theme of her other works, *What the Water Gave Me* scatters disparate elements into a bath filled with water. Despite visual form substituting for the written word, Kahlo's symbolism pervades her art and evokes an emotional attachment to the symbols democratizing her suffering. After all, in 1953, Kahlo herself was quoted in TIME Magazine as saying: "They thought I was a surrealist, but I wasn't. I never painted dreams. I painted my own reality". In this statement, her "reality" is not positioned as antithetical to surrealism but instead Kahlo offers a fantastical manifestation of a non-normative reception of the real world.

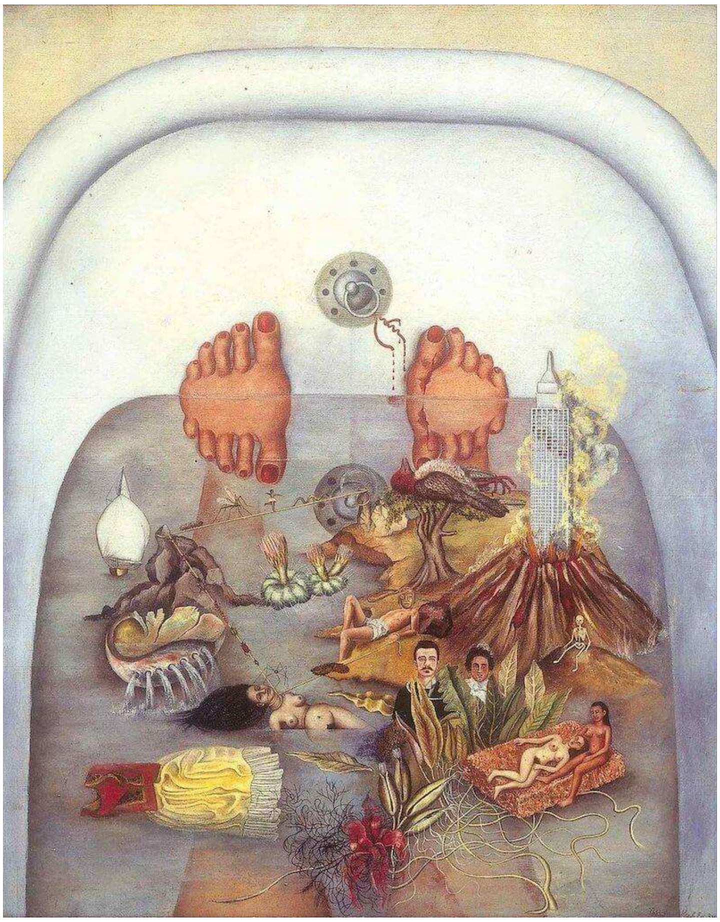

Fig. 1, Frida Kahlo, *What the Water Gave Me*, 1938.

Through her art, Kahlo centralises her disabled form in rejection of the restrictive parameters applied to the 'normate' body[3]. Rather than feature the gratuitous shape of the odalisque, the naked body central to *What the Water Gave Me* appears deformed – the toes on her right foot crippled by polio much like Kahlo's own[4]. The angle of the body presented within the painting compels the viewer to adopt possession of the disabled legs themselves: they gaze upon their own deformed body within the bath. As a result, the self-portrait becomes a universalising experience of Kahlo's story and dismantles the asexualisation of the marginalised disabled body. Kahlo circumvents the absence of a literary narrative through her construction of disabled form and perspective to project a sense of selfhood into the public sphere.

The image corrupts the form of a literary stream of consciousness by overriding a diachronic mode of temporality: all images are presented simultaneously and yet by the nature of the medium must have been constructed individually over an extended period of time. The constituent parts therefore come to represent the tangled formation of memories themselves and the juxtaposition of natural and man-made elements, life and death, interrogates the artist's acceptance of her life's trajectory. Painting from within the confines of her bed, Kahlo's artwork collapses any temporospatial delineation and embodies the isolation of chronic illness. I agree with Courtney et al in 'Frida Kahlo: Portrait of Chronic Pain' (2017) when they argue that because "Chronic pain, like many chronic diseases, can lead to suffering and social isolation […] the broad appeal of Frida's work relates to her ability to pull back the curtain and expose this marginalising experience" (91). When language ceases to encapsulate suffering, Kahlo's imagery illuminates her chronic conditions and nurtures the capacity for understanding an essentially alienating and incomprehensible state of pain.

The discrete images within *What the Water Gave Me* bear similarities to the pain scales adopted in clinical settings. The McGill Pain Questionnaire classifies pain into twenty sub-categories including "temporal", "punctate pressure" and "thermal" in order to provide "quantitative measures of clinical pain" (Melzack 277-299). Within these categories, pain is then assigned language such as "stabbing", "lancinating", "scalding", and "searing" to further pinpoint its precise manifestation in the body (Melzack 277-299). The positioning of an

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[3] This paper uses 'normate' as identified by (Rosemarie Garland-Thomson).

[4] Kahlo was diagnosed with Polio aged 6. This led to a distortion of her right leg and lifelong chronic pain. Andrea Kettenmann, *Frida Kahlo 1907-1954: Pain and Passion*, trans. by Karen Williams (Cologne: Benedikt Taschen, 2000), 10.

erupting volcano over the subject's right knee in *What the Water Gave Me* conjures ideas of "scalding" pain within the joint and the feeling of tightness associated with swelling, relieved only by the metaphorical eruption of lava out of the inflamed tissue. These images bypass the intermediary assignation of language to narrate Kahlo's suffering in a visual medium.

There is precedent for images being used by clinicians in lieu of a written articulation of pain: the NHS uses the 'Wong-Baker FACES Pain Rating Scale' to determine pain in children, neurodivergent and non-verbal adults. The 'Wong-Baker Scale' depicts six faces captioned from "0 – No Hurt" (a smiling face) to "10 – Hurts Worst" (a crying face)[5]. If the response to these pictographic alternatives to narrative is "to convey to a doctor to some extent what his or her patient goes through" then one may argue that they have succeeded in Charon's aspiration for Narrative Medicine (3). Thus, by considering Kahlo's paintings comparably, Narrative Art should also be considered an extension of Narrative Medicine.

Conclusion

By expanding the parameters of Narrative Medicine to include pictorial forms, we circumvent ableist biases. Galen Strawson argues in 'Against Narrativity' that "there are deeply non-narrative people and there are ways to live that are deeply non-narrative" (429). He continues that by demanding an inherently narrative construct of self,

> [We] hinder human self-understanding, close down important avenues of thought, impoverish our grasp of ethical possibilities, needlessly and wrongly distress those who do not fit the model, and are potentially destructive in psychotherapeutic contexts (429).

So, although Narrative Medicine seeks to explore the identities of sick individuals and provide a platform for self-expression, it currently erects constraints around the genre by prioritising those whose lived experience fits a conventional linear temporo-spacial model of narrative. As a result, the representation of sickness becomes slanted towards a neurotypical experience and reinforces prejudices against certain marginalised communities such as those who are unable

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[5] For validation of the Wong-Baker FACES pain rating see research completed by Gregory Garro et al, "Validation of the Wong-Baker FACES Pain Rating Scale in Pediatric Emergency Department Patients", *Academic Emergency Medicine*, 17.1 (2010): 50–54.

to present their lived experience in (what the dominant ideologies believe to be) a legitimate narrative form.

The Medical Humanities extends far beyond the role of "supportive friend" or "disruptive teenager" to medicine's dominant paternalism. The stories that emerge from this interdisciplinary field inhabit a complex conversation with our lived realities. Whilst Medicine depends upon the construction of an anonymous and uniform body that adheres to the classical presentations of disease within the clearly delineated parameters of anatomical textbooks, the stories that bleed out of the sick/dying are messy and complicated; they leak into the liminal spaces of the bio-psyche-social sphere and interact with other lives and events. Through Narrative Medicine, the Medical Humanities explore the nuances and complexities of identity which are absent in a medical reductionism. Pathographers demand the recentring of the otherwise marginalised sick/dying. By cultivating a space for these disparate voices – such as Frank, Sedgwick and Kahlo – Narrative Medicine bypasses the ethical hazard of truth telling and instead navigates the subjectivity of storytelling. Pattison warned that:

> We will know that medical humanities as a vibrant, pluralistic, experimental, risky movement has died when […] it excludes varieties of disciplinary perspective and performance and becomes an autonomous discipline in its own right (33).

If the Medical Humanities wish to thrive, they must therefore embrace the "vibrant, pluralistic, experimental, risky" nature of a more all-encompassing Narrative Medicine.

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