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ATTENDING TO THE PATIENT
Bioethics and Medical Literature

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1. Introduction

Robyn Bluhm's recent paper draws our attention to the critical reality that "neither bioethics nor the philosophy of medicine has paid much attention to the relationship between vulnerability and health or illness."[1] Robyn Blum states that "attending to vulnerability due to diminished health solves some problems in current accounts of health and disease and also allows us to better understand the ways in which health problems can change people's lives."[2] Her paper, together with the works[3] of scholars such as Rogers, Mackenzie and Dodd indexes the fact that, within the context of illness and healing, the nature of vulnerability is relatively under researched. These scholars add that by focussing on patients' vulnerability we are capable of illuminating the vital relationship between health and illness. For it is this very vulnerability, that is capable of granting us potentially profound insight into the social face of the illness and access to 'seeing' the person within the patient. I suggest that a medical 'blind spot' or 'ignoring' of patient vulnerability is not only embedded in (much of) the interaction between a large segment of health care workers and the patient, but is also insidiously present in much of the way that the medical literature is constructed. This proves to be 'circular' as the literature in turn is used as 'instructional' by the health care workers and medical practitioners,[4] who further structure their patient relationships along the lines of what the medical literature says.

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[1] Bluhm Robyn, "Vulnerability, Health and Illness," *International Journal of Feminist Approaches to Bioethics: Special Issue on Vulnerability*, 2012, 147-161, 147.

[2] Bluhm, "Vulnerability, Health and Illness," 147.

[3] Rogers Wendy, Mackenzie Catriona and Dodds Susan, "Why Bioethics Needs a Concept of Vulnerability," *International Journal of Feminist Approaches to Bioethics: Special Issue on Vulnerability*, 2012, 11-38, 11.

[4] I am opting for the (inclusive) term medical practitioner as I am not merely alluding to the doctors (in this instance the oncologists), but also to the extended web of nurses, radiologists, cardiologists, surgeons *et al.* who all, at some point in the trajectory of the unfolding diagnosis and treatment regime/s, see and consult with the cancer patient.

This paper is meant to contribute to the intellectual conversation on the notion of vulnerability initiated by researchers like Robyn Bluhm. I do this by focusing on medical literature, more specifically medical oncology literature. I relate Bluhm's arguments on vulnerability and philosophy of medicine to a discussion of bioethics in medical literature, and I argue that such a medical 'eliding' of 'patient-worth' in the literature is inherently unethical or '*adharmic*,' in other words it goes against the true duty of the medical practitioner, which is to take care of and attend to the person with the illness and not merely attend to (attempting to cure) the illness.

By drawing on an earlier study of mine with terminal cancer patients,[5] and the narrative insights from the qualitative interviews that emerged from the study, I engage theoretically with the argument that bioethics in medicine is not merely about ethical rules that govern how medical professionals ought to behave and enact their medical selves with the patient, but that it also extends to how the medical literature ought to be written for the interconnected community of medical students, practitioners and the patients. This is about recognising, as Robyn Bluhm points out, the patients' vulnerability. However, I add that we can gain a measure of phenomenological insight into some aspects of this vulnerability through narrative work and narrative inquiry with the patients, by permitting them to 'tell' us about their lived experiences with illness and health, and allowing these subjective insights and insider perspectives to shape aspects of medical literature.

2. Situating the Paper

In attempting to give us an idea of the phenomenological insight into the patient's experience of illness, scholars describe extreme or terminal illness as loss of control over bodily functions, and as a "betrayal of the body," the "increasing alienation from a body that an ill person experiences."[6] The sociologist Nick Fox points out that health and illness are 'phenomena,' that are, 'material' and 'experiential'[7] claiming that while diseases affect organs and cells, they also influence experience and identity. His contention, however, is that despite the elaboration of a social

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[5] Naidu Maheshvari, "Performing Illness and Health: The Humanistic Value of Cancer Narratives," *Anthropology Southern Africa* 35, 3&4 (2012), 71-80.

[6] Carel Havi, *Illness: The Cry of the Flesh,* Stocksfield, UK: Acumen Publishing Limited, 2008, 20, cited in Bluhm, "Vulnerability, Health, and Illness," 158.

[7] J. Fox Nick, "The Ill-Health Assemblage: Beyond the Body-with Organs," *Health Sociology Review* 20, 4 (2011), 359-371, 359.

model of embodiment, many scholars and practitioners still saddle themselves with an "implicitly or explicitly biomedicalised body as the location of 'health' and 'illness,' and as the ontological unit of sociological analysis."[8] This assertion is one that I find myself sadly agreeing with. Perhaps this point is most poignantly illustrated within the context of terminal illness and death. To the physician, death and the process of dying happens to the body in measurable and quantifiable terms, while to the patient, dying-and-death is what happens to them emotionally and through the (experienced) materiality of the body.[9]

My ethnographic study[10] was situated amongst a group of female cancer patients. This qualitative study attempted to 'listen' to the patients' 'stories' about their experiences of vulnerability within the context of their illness. These individuals were the patients and not the doctors and were thus normatively positioned as the 'hearers' and not the 'tellers' in the medical discourse that would have begun to take shape around the medical consultation. These women, in most instances, were terminal cancer patients[11] and to them cancer was semiotically and literally, about both death and dying. More importantly, and as the women shared, the illness was also about both the medical and social. This is the point of insertion for this particular paper as many of the issues that the women voiced in their narratives appeared to be 'visibly absent' from the medical literature. They did not merely speak about their illness, but rather their 'selves' as being ill. In other words, there was a profound awareness of their changing selves, in the context of the cancer. Many voiced that the doctors saw them as merely patients, not people, and that they were written about as clinical patients, as opposed to ill people. Many women voiced profound experiences of pain, vulnerability and a sense of 'disconnect' and shared stories of bodies that they had lost control over. An ill and in that sense, abject body is a "messy, sick, and damaged body,"[12] says Julie Kristeva.

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[8] Fox, "The Ill-Health Assemblage: Beyond the Body-with Organs," 359.

[9] Naidu, "Performing Illness and Health," 77.

[10] Naidu, "Performing Illness and Health," 77.

[11] The reason for narrowing the gaze on an illness such as cancer is simple. This is because for a disease that (in most instances) has come to signify death, it is powerfully alive within and on the body of the patient in ways that are at once both visceral and visual, and it (the illness) brings out the most heartbreaking vulnerabilities in the patient where the body appears to let you down in the most taken for granted aspects, as patients begin to lose control over their bodily functions.

[12] Kristeva Julia, *Powers of Horror: An Essay on Abjection*, New York: Columbia University Press, 1982, 2.

This was especially true within the context of the cancer patients who shared stories of extreme bleeding, extreme hair loss and what they felt to be embarrassing loss of bodily control. Their narratives revealed that cancer caused experiences of "brutish suffering"[13] in the form of disorder, powerlessness and pain.[14] The 'abject' body, because it may become unreliable or difficult to control, can compound the experience of alienation. These experiences also serve to create experiential and conceptual distance between the self and the body. Pamela van de Riet[15] talks about these kinds of bodily bleeding as a kind of corporeal irruption which can alienate the self from the body. In these conditions, the body becomes disconnected and alien in very personal ways. Almost all the participants in my study, spoke about intense and profound feelings of disconnect from themselves. However, these stories rarely make it to the pages of a medical journal. These shared stories in turn give credence to the assertion that the biomedical model sculpts a particular understanding of the ill person that is reductionist at best, and that can perhaps be claimed as stripping much of the humanity off the patients.

3. Literature, Medical Literature and Ethics

The grand design of the biomedical model can thus be seen as reducing illness to a biological mechanism of cause and effect,[16] while the practice of medicine itself is broken down into smaller and smaller 'medical bytes' in the name of specialisations; the oncologists, the cardiologists, the radiologists, the surgeons and so on.[17] All of this is further reflected in how the medical literature is constructed, and how the patient is viewed within medical health models and praxis. The surgeon deals with the tumour that

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[13] Kristeva, *Powers of Horror*, 2.

[14] In my 2012 ethnographic study with the terminal cancer female patients, the informants, Rose and Mary's cultural backgrounds and personal grooming habits indicated that they had been fastidious about hygiene. Thus bleeding and coughing up blood in the context of their illness was met with revulsion. They both spoke about deep feelings of dirt. However, they spoke about dirt in ways that transcended bodily dirt. It was dirt that they felt they could not wash off (be rid of), as it violated their coherent boundaries as women. Naidu, "Performing Illness and Health," 74.

[15] Van der Riet Pamela, "The Sexual Embodiment of the Cancer Patient," *Nursing Inquiry*, 5, 1998, 248-257, 495.

[16] Wong Nancy and King Tracey, "The Cultural Construction of Risk Understandings through Illness Narratives," *Journal of Consumer Research*, 34, 5 (2008), 579-594, 581.

[17] Naidu, "Performing Illness and Health," 71.

has to be removed, while the oncologist deals with the tumour that has to be treated and shrunk with neoadjuvant chemotherapy, in preparation for the surgery, while the nurse administers the chemotherapy itself. It is not (merely) one individual that takes care of the ill person. Perhaps we can be facetious and suggest no one(!) takes care of the ill person. For although it is multiple practitioners attending to the patient, it is actually no one attends to the ill person. The tumour has an attendant, as do various body parts when they begin to creak, crack and give way under the incredible strain of (toxic) chemotherapy and radiation. The oncologist will be called in more often as will the specialist physician, who is meant to deal with the complications that invariably and mercilessly arrive in the wake of the powerful drugs injected into the cancer patient. So the various body parts have their attendants, while quite often there is no one inside the medical profession, for the patient, as a person. Of course one understands that these multiple specialists bring multiple skills, and that no one single practitioner can be expected to be an expert in all the subspecialisations. However, this does little to console the ill persons who feel increasing lost amongst the specialists, none of whom actually know them.

One is not suggesting that each medical specialist, the oncologist, the surgeon, the radiologist, etc. begin to spend extended time with each and every ill person. It is the quality of the time spent and the meaningfulness and mindfulness of the interaction that is vital. It is insights that could be gained by each of the various medical practitioners, through the medical literature, while they are being trained and throughout the duration of their practice, that now becomes critically important. If the medical literature is barren and bereft of the social face of the illness (like cancer) and of the actual vulnerabilities of the patients, there is very little that the practitioners are learning of the ill person, beyond merely the medical.

In many instances, and certainly in popular usage (I myself use it in this paper), the term 'patient' is fairly innocuous. However, within the context of medical literature, and this is what the participants of my earlier study were attempting to share with me, the term moves beyond the denotative and connotes a de-'facing' and homogenising of the ill person into the clinical/medical patient.

While literature in its broad sense (and as a stand-alone word) refers to written works of creative and artistic dimensions, appending a qualifying term immediately in front of the term 'literature,' as in 'anthropological literature' or 'sociological literature,' or as in this case, 'medical literature,' changes the textual and connotative complexion of the term, and the term comes to now refer to more formally structured written works, and in many instances, disciplinary-based articulating texts. The paper thus comprehends ‘medical literature’ as it is commonly understood, that is, as referring to articles in journals, texts and books committed to the discipline of medicine. My concern here is the ‘ethics’ in medical literature, or the embedded values and sense of ‘right’ within the texts, in terms of the (wholly clinical) descriptions of illness and health, and especially medical literature that purports to describe the patients who are ill.

The British sociologist Nick Fox,[18] with an abiding interest in the politics of medicine and health, draws our gaze to the need for a reorganisation of the medical ‘care relationship,’ claiming that these are powerful sites for destabilising the normative status quo within the health fields. He asks for a re-appraisal of issues of structure, identity and knowledge in medical sociology and points out that it has been complicit in the creation of particular constructions of ‘the patient’ and of ‘health’ and ‘illness’[19] within medical knowledge. My point is that all of this comes to be reflected within discourse and the medical literature, which of course is itself dictated by a bio-medical discourse and ‘understanding’ of the patient. Philip Tovey pointed out as far back as 1992(!) that we are in an “era in which ‘evidence-based medicine’ (EBM) is increasingly directing research and practice, and the randomised controlled trial remains dominant in the collation and definition of that evidence base”[20] which comes to be put forward in medical literature.

More recent social sciences accounts working within a wider social framework[21] have however agitated against such a positivistic stance, and have become acutely aware of the limitations of traditional medicine in comprehending, and therefore meaningfully assisting, the experience of the patient. While there will always be the need for some purely clinical studies, which are necessarily written in a grammar of statistics and percentages and with an analytical vocabulary, there is equally, I argue, an

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[18] J. Fox Nick, *Postmodernism, Sociology and Health*, Toronto: University of Toronto Press, 2004; *The Body*, Cambridge, UK: Polity, 2012.

[19] Fox, *The Body*, 6.

[20] Tovey Philip, “Narrative and Knowledge Development in Medical Ethics,” *Journal of Medical Ethics* 24, 3 (1998), 176-181, 177.

[21] J. Twigg, “The Body in Social Policy: Mapping a Territory,” *Journal of Social Policy* 31, 3 (2002), 421-439; S. Harrison and C. Smith, “Trust and Moral Motivation: Redundant Resources in Health and Social Care?” *Policy and Politics* 32, 3 (2004), 371-86; Julia Twigg, *The Body in Health and Social Care*, Basingstoke: Palgrave Macmillan, 2006.

urgent need for medical texts and literature that describe the lived experiences of the patient woven into their discourse and description of the illness. As it stands at present, much of that kind of personal perspective is considered 'popular' literature and finds space on the shelves marked, 'Autobiographies' and 'Personal Cancer Stories' or 'Illness Stories.' While the patients read these, the practitioners (tend mainly) to read the medical literature. This appears to me as a bizarre disjunction. For gone are the days where we can naively assume that only the medically trained can, and should, be reading the so called medical literature. The average person wishes to be informed of what is happening to them. Yet much of the medical literature serves to alienate this section of the audience and fails to come close to conveying the patient's sense of loss within the contexts of profound life threatening illnesses such as cancer[22] and HIV/AIDS.

As Twigg reminds us, and borne out my ethnographic work with the women with cancer, for many patients, the experience of modern medicine, especially hospital-based medicine "is a disjunctive one, involving not just pain but also dislocation, objectification and a denial of their sense of embodiment."[23] Traditional medicine and traditional medical praxis construes and constructs the patient in positivistic or clinical terms within the medical literature. The circular path that I alluded to earlier is more apparent when we realise that the inscriptional approach and practices offered by medical treatments, especially within disease like cancer, is itself underwritten by epidemiological and environmental impact studies, which forms part of the corpus of medical literature.

We are compelled to become increasingly vigilant of the dominant hegemonic ideologies of illness and body, in medical texts and in medical praxis, through which we are increasingly being obliged and compelled to enact illness and health. Poststructural approaches that are cognisant of pluralistic perspectives offer some measure of vigilance as they challenge fundamental canonised positions in social theory, and allow a destabilising and re-reading of central hegemonic ideas in medical health and the literature. Foucault's[24] critical analysis of the medical gaze and the disciplinary power of medicine, which he claimed as being exerted over individual bodies and the (medical) body politic, is a good example.

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[22] Naidu, "Performing Illness and Health," 2012.

[23] Twigg, *The Body in Health and Social Care*, 98.

[24] Foucault Michel, *The Birth of the Clinic: An Archaeology of Medical Perception,* New York: Vintage, 1975; *Discipline and Punish: The Birth of the Prison,* New York: Vintage, 1979.

4. Care Ethics within the Medical Literature: A Form of Dharma?

My position is that ethical perspectives are potentially able to exert a moral[25] power in reshaping the 'care relationship' as reflected in medical texts, and articulated in medical practice. This may offer a counter to our contemporary commodity culture (which exists even within the medical world). For the 'commoditization of health care' within a market economy limits personal contact between doctor-patient, in the interest of efficiency.[26] While this may not be completely so in some health care clinics and hospitals, there is nevertheless a push for quicker turnover in the name of limited resources and placing patients on a triage. All of which further erodes into meaningful contact time (and care) between the patient and the medical practitioner.

Feminist theorists have used the term *care ethics* to describe a relational approach that does not rely on "rubrics of adjudication such as rules or consequences,"[27] in other words the so called consequences of affording patients 'too much time' (extra time taken to 'really listen' to the fears and questions of the patient that appear to extend beyond the medical). Working from both a philosophical and a critical feminist perspective, Maurice Hammington contextualises care ethics within the patient-medical practitioner dyad in a manner that makes sense to me. In fact it makes *dharmic* sense.[28] Hammington describes relational care ethic as being both "a practice and a value."[29] The notion of 'care' conceptualised thus, combines a disposition of openness and connection to the 'other,' in this instance, the patient, and is argued as being able to foster empathy, understanding, and actions on their behalf (from the practitioner). Perhaps an even more powerful insight from Hammington is that 'care' is a relational approach to morality, born out of the ontological notion[30] that human beings are inherently connected. His point is

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[25] Though terms such as *ethics* and *morality* are contextual, and have situational meanings within diverse cultural communities, I am using these terms in their broad universalistic and cross cultural sense of meaning 'respect' for the patient as a person.

[26] M. Cancian Francesca, "Paid Emotional Care: Organizational Forms that Encourage Nurturance" in *Care Work: Gender Labour and the Welfare State*, ed., Madonna Harrington Meyer, New York: Routledge, 2000, 136-48, 141 cited in Hamington Maurice, "Care Ethics and Corporeal Inquiry in Patient Relations," *International Journal of Feminist Approaches to Bioethics* 5, 1 (2012), 52-69, 53.

[27] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 53.

[28] I am using the word '*dharmic*' here to refer to the sense of 'rightful duty,' in this instance of the medical practitioner towards the patient in his/her care.

[29] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 54.

[30] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 54.

that a common theme in this kind of care-ethics is that of a "heightened sense of attentiveness to the one cared for" as a kind of "engrossment" and "concentrated attunement to the other."[31] All of this is certainly not a new or a startlingly novel notion within many religious traditions, especially within the non-dualistic religious traditions. It is however, a 'fresh' perspective and less known within contemporary philosophy of medicine. It also offers exciting ethical possibilities within medicine that perhaps takes us back to what may have originally been meant regarding taking care of the patient, and encapsulated within the following quote: "The traditional understanding of beneficence, dating back to Hippocrates, is the idea that physicians have a duty to benefit the patient."[32]

The codified Hippocratic Oath[33] can perhaps be considered as the quintessential piece of medical literature. The Oath opens with the newly qualified doctors pledging: "I do solemnly vow, to that which I value and hold most dear." The oath itself comprises eleven pledges that the newly trained doctor commits to. Pledge No. 1 promises to honour the profession and refers to service to humanity, while pledge No. 8 talks about sacred trust and 'keeping aloof' from 'wrong.' Most revealingly, pledge No. 6 and No. 7 refers to the profession of medicine in compassionate and humanistic terms, and refers to medicine as both an art and a science! The young doctors close the pledge by swearing that "I make this vow freely and upon my honour." Thus the humanistic values of care, honour and respect for both the profession and the patient, as simultaneously a value and a practice, is deeply embedded into the fabric of the oath. This is not to say that there are no nurses or doctors and other health care workers who currently practise their profession with honour and dedication. The point though is that, it is becoming increasingly difficult, within a biomedical model, for such a practitioner to fully honour his/her profession as Hippocrates meant – *as both an art and a science.*

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[31] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 55.

[32] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 62.

[33] Excerpts from the Hippocratic Oath: 1) That I will honour the Profession of Medicine, be just and generous to its members, and help sustain them in their service to humanity; 6) That I will lead my life and practice my art with integrity and honour, using my power wisely; 7) That above all else I will serve the highest interests of my patients through the practice of my science and my art; 8) That I will maintain this sacred trust, holding myself far aloof from wrong, from corrupting, from the tempting of others to vice. Retrieved Online on 4 March 2013. http://www.med.cornell.edu/deans/pdf/hippocratic_oath.pdf

It is of course not unusual to meet the caring oncologist. Yet this oncologist is often compromised by the medical system itself, into enacting particular kinds of understandings and interactions with the patient. This is borne out in the narratives shared by my participants.[34] Some of the women mentioned oncologists who they felt were very caring and respectful. However, just as many pointed out that even when they met "that kind of oncologist," *within* the consulting room, they were often greeted by the clinical approach of the radiologists outside. Conversely, other women mentioned that the while the nurses were sympathetic, many of the doctors were more dispassionate. True, as pointed out by the reviewer of this paper, in many countries, including India and parts of Africa, the services of Catholic nuns and institutions are praised for their compassionate care of their patients. One adds though, that these individuals are not working with a bio-medical discourse and a bio-medical model of illness and health, or with a bio-medically constructed 'patient.' Within such a model, are situated the structural binaries of 'illness and health,' the 'ill person and the healthy person,' the 'patient and the doctor'. While the latter labours under a model of care that is becoming increasingly ideological and consumerist, the nuns work within a totally different epistemic and understanding of person and duty (*and care*).

5. Narrative Ethics and Dharma

How does the 'care ethic,' which is praxis rather than textual, relate to medical literature you may ask? It is at this juncture that narrative ethic makes its appearance. We arrive full circle back at my opening comments: "'gaining phenomenological insight into patients' vulnerability through narrative inquiry with the patients, by allowing them to 'tell' us about their lived experiences with illness, and allowing these subjective insights and insider perspectives to shape aspects of medical literature.'"

The writer and specialist oncologist Siddharth Mukherjee in his monumental book, *The Emperor of All Maladies: An Autobiography of Cancer*, puts it wells when he says: "A patient, long before [s]he becomes the subject of medical scrutiny, is, at first, simply a storyteller, a narrator of suffering, a traveller who has visited the kingdom of the ill."[35] Put simply, a narrative ethic asks whose story is being told, and by whom. It also asks whose interpretive framework is being given authority. These

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[34] Naidu, "Performing Illness and Health," 2012.

[35] Mukherjee Siddhartha, *The Emperor of All Maladies*, New York: Scribner, 2010, 46.

critical 'who' questions afford us a post-structural interrogation around the construction of (medical) knowledge. A narrative ethic may also identify that the 'voice' of those on the "margins of discourse," and reveal that their narratives and interpretations, "has something to offer those, such as doctors, and may alert us to aspects of practice which are experienced in ways that are not intended."[36] Narrative ethics is also concerned with transformation. It allows us to reflect upon the fundamental assumptions and tenets of a practice or discourse, the impact of those assumptions upon the most vulnerable, and creates the space for transforming the practice to incorporate the insights of the patient narrators.[37]

Nicholas and Grant point out that there can be a narrative nature to medical knowledge and highlight the place of (patient's) 'story' in medicine, and the extent to which it can structure medical knowledge and play a central role in the transmission of this knowledge, through the medical literature one adds. After all, we cannot deny that 'story' "forms the basis of medical care in the narratives that patients bring to their doctors and in the narrative the doctor constructs in relation to the patient."[38] Stories or narratives are said to underpin social reality and 'social (constructed) reality may be a reflection of the individual's thoughts and actions. Let us for a moment, 'play' with the notion of 'story' as a metaphor, and stretch its representative limits.

The 'story' or 'narrative' that the practitioner offers back to the patient may well be 'written' in a 'language' that is unreadable and incomprehensible to the patient. The medical practitioner's story often has a storyline (diagnosis and prognosis), a plot (treatment regimes – radiology, chemotherapy, surgery) and characters (the radiologist, the oncologist, the surgeon) as well as a stage of well laid out props (medical linear accelerator for the radiotherapy, chemotherapy drugs, the operating theatre for the surgical enactments). In some ways all of this is (purportedly) designed around the main protagonist, the patient. Yet the patient has not much of a 'spoken role.' The patient is the silent actor, who is in large part, scripted to follow the direction of the practitioner.

For it is in the initial visit that the doctor/oncologist listens intently to the description of the symptoms told/narrated by the patient in order to

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[36] Nicholas Barbara and Gillett Grant, "Doctors' Stories, Patients' Stories: A Narrative Approach to Teaching Medical Ethics," *Journal of Medical Ethics* 23, 5 (1997), 295-299.

[37] Nicholas and Grant, "Doctors' Stories, Patients' Stories," 297.

[38] Nicholas and Grant, "Doctors' Stories, Patients' Stories," 296.

construct his pathology. The subsequent visits see the medical practitioner normatively positioned as the ‘teller’ as he/she begins to unpack the treatment regime within the ‘medical science.’

6. (Ethical) Medical Literature and Narrative Medicine

For me it is narrative medicine that holds the greatest promise in attempting to bridge what may be perceived by some as a gap between social and natural sciences. For narrative medicine can be seen as possessing ‘soft edges’ or potentially porous boundaries between the social and medical sciences[39] and able to potentially reshape a more ‘ethically conscious’ medical literature (and a cohort of practitioners who are also ethically literate!).

It was Trisha Greenhalgh who reminded us over a decade ago that “appreciating the narrative nature of the illness experience” in essence “does not require us to reject the principles of evidence-based medicine.”[40] She pointed out that such an approach does not necessitate an “inversion” of the established hierarchy of evidence to the extent “that personal anecdote carries more weight in decision making than the randomised controlled trial.”[41] She reminds us that it instead invites the use of an interpretive paradigm through which it is understood that the patient experiences illness in a very particular manner.

Narrative medicine has also been put forward as one solution to an increasingly impersonal medical environment, where educators in the medical humanities, turn to narratives and narrative studies to teach medical students “an emotionally fulfilling and interpersonally related professional practice.”[42] Such an approach is seen as a way to commit to “fostering the use of the humanities, social sciences, and the arts as a lens for examining issues in health, medicine, and healing.”[43] Sayantani Dasgupta a Buddhist and a medical practitioner, claims that illness narratives written by those suffering illness, (and researchers collecting such narratives) form a genre of writing that has grown in the past few

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[39] Naidu, “Performing Illness and Health,” 78.

[40] Greenhalgh Trisha, “Narrative Based Medicine in an Evidence Based World,” *BMJ* 318 (7179), 1999, 323-335, 323.

[41] Trisha, “Narrative Based Medicine in an Evidence Based World,” 323.

[42] Dasgupta Sayantani, “Between Stillness and Story: Lessons of Children's Illness Narratives,” *Journal of American Academy of Paediatrics* 119, 6 (2007), 1384 -1391, 1384.

[43] Dasgupta, “Between Stillness and Story,” 1384.

decades, adding that such stories or pathographies[44] are "a postmodern phenomenon, in which narratives authored by the ill give voice to an experience that was once narrated solely by the medical establishment."[45] While this growth is appreciated, it is still however, far from an exponentially adequate growth and is yet to filter down to a large segment of practitioners who remain pedantic in their positivistic approach. Yet, the process of transforming patient histories into medical language – in its representation of subjective experience, gives us critical and vital access to the perceptions and valuation of the ill.

Philip Tovey proposed that, not only do personal stories offer a valuable source of insight into the empirical reality of situations and events, but that we are also able to make the leap from the ideographic to the generalisable. According to Tovey, in this way the argument that stories are insufficient for medical ethics falls away.

> With empirically gathered stories, established theories, principles and expectations are opened up to the challenge of accounting for numerous real-life situations and experiences. The aim of using the approach is as a means to extend knowledge about "patient worlds," to 'enter' those worlds empirically and thereby contribute to a multidisciplinary approach to these complex issues which is already incorporating qualitative research data.[46]

All of this quite understandably and very legitimately demands research rigour which ideally would provide the means for the "elevation of individual stories" where a "contribution to the evidence base medicine"[47] can be made. This re-affirmation of medicine as more than only scientific knowledge and technical proficiency needs to be accelerated into both literature and praxis.

6. Conclusion

Fox's discussion around developing a perspective for revealing the politics of 'health talk' or 'illness talk,' points out what is becoming increasingly

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[44] See Aronson Jeffrey K., "Group Autopathography: The Patient's Tale," *British Medical Journal* 321 (2000), 1599-1602.

[45] Dasgupta, "Between Stillness and Story," 1386. See also the works Charon Rita, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," *JAMA* 286, 15 (2001), 1897-1902; "What to Do with Stories: The Sciences of Narrative Medicine," *Canadian Family Physician* 53 (2005), 1265-1267.

[46] Tovey Philip, "Narrative and Knowledge Development in Medical Ethics," *Journal of Medical Ethics* 24, 3 (1998), 176-181, 181.

[47] Tovey, "Narrative and Knowledge Development in Medical Ethics," 177.

obvious; that illness is never merely just illness. My plea is that, as researchers working on social issues around health, and in our bid for reorganisation of the care relationship and of care models, we need to push for greater recognition of that which may seem deceptively obvious, but which appears to elide the 'medical gaze' of many, that in dealing with 'illness,' we are actually dealing with 'ill people.' We need to see the ill person as a whole person rather than merely the patient and bearer of symptoms. In cultivating this 'whole person' understanding doctors would 'stretch' their imagination and empathy, which their formal training and the formal instructional medical literature and clinical case studies might have encouraged them to disregard as irrelevant.

We need to thus add to the urgency of such a perspective (beginning in medical literature and further articulating in medical praxis) by proposing a more humanistic and ethical postmodern medical social science, that in turn constructs the medical literature. For me such a perspective allows a privileging of the patients' experience of illness. Good medical care involves a role relationship besides being that of a specialist, a human relationship.

June Goodfield's observation, made all of thirty seven years ago, is still potently true, and one that needs to be held in sight of the medical gaze. Goodfield asserted that "Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact."[48] Hammington reminds us that an overlooked facet of caring is its "epistemic contribution." For Hammington, caring can be conceived as inquiry; an active effort to know others for the purposes of understanding that may lead to deeper caring.[49] Again for me, this speaks directly to our sense of interconnectedness and has the potential to transform patient and practitioner interaction. Vulnerability may well be "an ontological condition of our humanity"[50] and attending to this vulnerability is attending to both the ill person and our own (rightful) duty and humanity.

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[48] Goodfield June, *The Siege of Cancer,* New York: Random House, 1975, 219.

[49] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 56.

[50] Hamington, "Care Ethics and Corporeal Inquiry in Patient Relations," 56.