
**Traversing Pathographies and Decentering the Hegemonic Reading Practices
in Medical Humanities: A Study on Arthur.W.Frank's
*The Wounded Storyteller***

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Abstract: The approach of medical humanities in contemporary literary studies has deepened our understanding of individuals who struggle with life due to illness and it has increased the need for inclusivity of their narratives within the ambit of literary discourse. Arthur. W. Frank's *The Wounded Storyteller*, an illness memoir or pathography interlaces his own experiences as a cancer survivor giving a public voice to his private vulnerability. The individual world is tremendously disrupted by suffering a stigma as society has a negative perspective of illness leaving them the marginalized 'other'. In analyzing the broad field of Medical humanities, one can come to a premise that a society can be classified on Marxian model as people with good health on the superstructure and with ill health at the base. Such stereotypes also affect people's perception of looking at pathographies or illness narratives in a depressing way. This paper attempts to analyze Arthur. W. Frank's *The Wounded Storyteller* from the cultural lens of Stuart Hall which clearly positions the readers of pathographies to be operating with a hegemonic cultural bias while decoding the illness experience of patients and also to de-center the cultural notions attached to illness in a society driven by values of health and well-being.

Key Words: Medical humanities, Pathography, Inclusivity, Cultural Theory, Hegemony, Marginalized, Health

Introduction: Medical Humanities is an emerging interdisciplinary field in literary studies. It deals with the application of humanistic principles in disciplines like literature, history and philosophy to the field of medicine. The domain of medicine has been increasingly focusing on the scientific and the technological advancements giving little importance to Arts and Humanities. The field of medicine is considered as a whole narrative process that embodies

the story of illness, health and relationships. A humanistic approach and a spirit of enquiry have been essential to both the physician and the writer. There is an increased focus on how individuals in society need to grapple with diseases, illness, suffering and trauma and greater emphasis on the physicians and the society treating the patients with utmost care and sensitivity. The patients and survivors have given expression to the experience of illness and agony through their writings.

Their pathographies have served as apertures into real life experiences of the patients and their journey into treatment, recovery and also death. This medical narrative is usually the firsthand account of patients but is also sometimes authored by the family or physicians who have experienced it as a witness. Pathographies also reflect the existential dilemma, emotional distress and the epiphanic realization of the trivialities of human existence. Pathographies are highly subjective bordering on an existential quest for a non religious writer, extremely nihilistic, who considers it as an aesthetic substitute for religion in a secularized world. Some writers explore spiritual dimensions as severe illness brings about a heightened spiritual interest seeking meaning and refuge in the transcendental thereby gives way hope for life.

Pathographies concern the attempts of individuals to orient themselves in the world of sickness- the world Susan Sontag calls “the kingdom of the sick” (1979-3) - to achieve a new balance between self and reality, to arrive at an objective relationship both to experience and to the experiencing self. The task of the author of pathography is not only to describe this disordering process but also to restore to reality its lost coherence and to discover, or to create a meaning that can bind it together again. (Hawkins 3, 4)

Pathography can be considered as stories of survival and also adventure in the manner of Robinson Crusoe surviving a terrible storm at sea than waking to a new catastrophic strange world. The literary world is familiar with survival stories about the natural or environmental disasters, war ravages, shipwreck, miraculous landing after a space travel, hostages and prisoners at concentration camps where ordinary people encounter extraordinary survival situations. Pathographies resemble the struggle of individuals in insurmountable circumstances where the bodies fight the marauding sickness in a situation where their own antibodies turn against them causing immediate destruction of the orderliness and coherence of their lives. Such narratives bring us to light the absence of order and are forced to contend with the sudden onslaught of disease and painful treatment procedures. Though pathographies are laced with a didactic purpose of narrating illness with practical information, in terms of its authorial intent it is classified into three broad categories. Pathographies tend to fall into three groups: testimonial pathographies, angry pathographies, and pathographies advocating alternate modes of treatment.(Hawkins 4)

The pathographies that bear testimony to the author's illness fundamentally brings our attention to the narrator's thoughts and his feelings which in turn serves to reinforce an optimistic perspective towards therapies and manage the trauma caused by it to the readers.

Marilyn Synder's *An Informed Decision*, a testimonial pathography is written for women who suffer from breast cancer, Joyce Slaton Mitchell's *Winning the Chemo Battle* helps the readers and other patients to navigate successfully through chemotherapy and improve the quality of their lives, Paul Kalanithi's *When Breath becomes Air* explores themes of life, death and relationships and Herbert Conley's *Living and Dying Gracefully* deals with author's experience and confrontation with pain and death. These testimonial pathographies with a didactic approach help the readers and patients to negotiate changes in their life with altruistic concern by creating a model or mirror of their life experiences.

Over the years pathographies have demonstrated a major cultural shift in representing a discontent for medicine and the problems caused by therapies and procedures more than the illness. A homogeneity of experience of the authors and their narratives placing trust and building relationships with the physicians have slowly been replaced by their anger due to prolonged hospitalization, callous and dehumanized attitude of the medical practitioners lacking care and concern, the physicians taking advantage of the vulnerability of the patients and working in the interest of the organization or insurance companies and failure of treatments. Angry pathographies have started to raise concerns over the way in which illness was looked upon lacking empathy of the entire medical system rather than providing a sense of courage and support to the ailing patients. Sue Baier's *Bed Number Ten* also provides an angry narrative of the indifferent medical care provided to her at the intensive care unit. Baier is completely paralyzed as she is afflicted with Guillian- Barre syndrome and she has recorded the mistreatment and complete disregard to her pain and suffering. Baier asks,

Was I paranoid to want to be treated as a human? To be asked how I felt? Did you sleep well? Are you comfortable?...There were so many little things constantly, one after another- indignities that led to my desperations. (194)

The third category of pathographies have started to stem from absolute dissatisfaction with the practice of medicine in contemporary times and propagated alternate modes of therapies that firmly believed in the inner resources of one's own self namely the mind, the psyche and the spirit. These pathographies believe in the boundless capacities of the mind and the therapeutic success partly or wholly determined by the patient's attitude and their will to live. These narratives have even challenged the Cartesian concept of the duality of the mind and body by introducing a new phenomenon of the interplay of the body and mind, the physical and the mental faculties to facilitate healing in a more holistic way. Some pathographies also suggest alternate modalities of treatment like acupuncture and naturopathic remedies. Such narratives serve as a reader's guide to treat sickness in an optimistic and hopeful way. The common rationale for writing a pathography is primarily to communicate their excruciating experience and the desire and need to find a response from the readers to their trauma through literary expression. Pathographies in the recent years have become so compelling to readers as it records and describes the various dimensions of the

experiences of men and women facing real life crisis. It is more appealing to the readers as it attempts to give form and shape to their deepest fears and hopes.

This paper analyses Arthur W Frank's pathography *The Wounded Storyteller* in the light of medical humanities and attempts to portray a de-centered narrative of hegemony and calls for readers not to develop a cultural dislike for illness stories. Arthur W Frank is an eminent sociologist and a scholar in the field of medical humanities whose interdisciplinary approach bridges domains of sociology, medicine, ethics and healthcare marking a significant contribution in Narrative medicine as he believes in the healing potentials of storytelling due to his understanding of the importance of illness narratives. *The Wounded Storyteller* marks his journey through the labyrinths of illness and his narrative challenges the conventional and hegemonic notions of the way in which sickness is perceived. He explores through his personal stories his enduring maladies and illuminates the readers to the fact that unpretentious sharing of one's experience can provide motivation and tool for healing and strength. He believes in connecting to a larger group through his individual voice thereby inspiring them to overcome pain and the vulnerability caused by illness.

Arthur W Frank has been diagnosed with cancer in 1986 when he has just turned 40 after surviving a fatal heart attack with the condition called Ventricular tachycardia, a year ago slowly gliding himself into the world of illness. While writing this seminal work *The Wounded Storyteller* Arthur W Frank distinguishes between narratives and stories. According to him, the narratives exhibit a fixed template with plot structures whereas stories are spoken expressions of narratives. His first type of narrative is termed as 'Restitution stories' combining authenticity and truth of the illness experience where the medical workers play an important role in the story by eventually restoring the lives of the patients through their treatment while the patients are relegated to a passive observation of the treatment procedures. Arthur W Frank terms his second narrative to be 'Chaos' or the anti-narrative which gives rise to stories of inevitable decline in the health of the patient where therapeutic intervention becomes a failure. The Chaos narratives reveal the fact that the patient requires the presence and attention of the medical worker in the room to ease out his fear. The third type of narrative is what he terms as 'Romance' which is the form of a quest narrative where the person stops to see himself as just a patient and looks at illness as a kind of calling and perceives it beyond understanding the reality of death and makes living a responsibility by peering through his chaos and becomes the protagonist of his quest narrative.

The restitution narrative is the first of the three types elaborated by Arthur W Frank that encourages the readers to have a closer attention to the particularity of individual experience told by ill persons in their stories. According to Arthur W Frank every narrative reflects strong cultural and personal stand points or perspectives. Contemporary dominant culture views health as one having a normal condition and every ill person has the desire for restoration of his health.

The plot of restitution has the basic story line, “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again”. This story line is filled out with talks of tests and their interpretation, treatments and their possible outcomes, the competence of physicians and alternative treatments. Metaphoric phrases like ‘as good as new’ are the core of the restitution narrative. Such phrases are reflexive reminders of what the story is about: health. (Frank, 77)

The plot structure in restitution narrative is an ancient concept and Arthur W Frank quotes the sufferings of Job in the Bible and his restoration of wealth and family. This interpolation of restitution plot shows the power of such storyline even in Canonical texts. The restitution story also becomes a culturally accepted hegemonic narrative as it breaks down the fear of mortality. In restitution stories the medical workers also play an active role and Arthur W Frank says,

To be fixable the body has to be a kind of machine. A Nobel Prize winning physician was interviewed in the morning paper. He suggested that for the reporter to understand his work he should think of the body as a television set and an elaborate analogy followed. Restitution requires fixing and fixing requires such a mechanist view. The mechanist view normalizes the illness. Televisions break and require fixing and so do bodies. (Frank, 88).

The main aspect of restitution narratives is directed towards two aspects. The individual narrator of pathography achieves the purpose of understanding the fact that the ending is just a return to the beginning where their former self enjoys the phase of ‘good as new’ before the advent of illness and overcomes his sickness in a heroic way. On the other hand, culturally restitution narratives affirm the fact that breakdowns of illness can be treated and fixed and their usual trajectory of life remains unperturbed where normal life is restored after a brief disruption caused due to illness. A hegemonic dominant position of reading always affirms the readers of hope after illness and they wish to decode aspects of remedy, progress and restoration of their health. Ill people who tell restitution stories practice their own banality of heroism. They live out illness as a matter of doing their jobs as patients, preparing for the future after illness, and getting through their own days. The restitution stories precisely because it treats sickness as banal, displays a heroism in the face of bodily breakdown. (Frank, 93).

Arthur W Frank Also points out that restitution stories have certain limitations. It is the postmodernist deconstruction of the concept of mortality. The reading communities do not wish to encounter sickness, decline and death as these stories provoke anxiety and fear thereby always seeking order and happy ending. The dominant hegemonic culture code seems to have been established also in the religious texts with regard to sickness. Arthur W Frank points out:

“Blessed are the poor in spirit, for theirs is the Kingdom of heaven” (Mathew 5:3). The greatest chaos stories are the first despairing verses of many of the Psalms; the Psalm’s

message seems to be that redemption of faith can only begin in chaos. Tragically, those who are most destitute are often beyond such solace. For the poor in spirit to recognize their blessedness, some reflective space is required, and that reflection is what poverty, like unremitting pain, denies. (Frank, 114)

When treatment procedures do not work for the patient, he or she is left with no other story to depend on and restitution stories do not work if the person is dying and his illness continues to remain chronic. So he points out the need for other forms of stories to be created. When there is no hope for life, restitution stories are available to patients to only conjure up a life of pretense. This gives rise to another form of narrative which Arthur Frank terms as Chaos narratives.

Chaos narrative is the inverse of restitution. Unlike restitution narratives where the plot envisages life after illness, the plot of Chaos narratives presents chaos and disorder provoking anxiety and revealing vulnerability, failure and futility. Arthur W Frank perceives restitution narrative as something that reassures the reader of hope and happy ending to their suffering, however bad their journey seems to be.

Job with his new family and cattle, is basking in God's graciousness. Chaos stories are Job taking his wife's advice, cursing God and dying. (Frank, 97).

The narrator of Chaos stories are truly living the life of chaos and the reader who decodes from the dominant hegemonic position can only grasp the edges of their wounds and cannot comprehend the agony that goes down to the bottomless depths. The author believes that chaos stories can only be told but cannot be lived. Chaos reflects the medicine's incapacity to control the illness and people living these stories present to the readers of the fact of how medicine is seeking to maintain a pretense of control, leaving them emotionally and physically battered as seen in the following lines:

On the control dimension, the body telling Chaos stories defines itself as being swept along, without control by life's fundamental *contingency*. Efforts to reassert predictability have failed repeatedly, and each failure has had its costs. Contingency is not exactly accepted; rather it is taken as inevitable. Denials of the chaos narrative often begin with the listener asserting how, in such circumstances he would find a way out. (Frank, 102).

Chaos narratives thus serve as an anti-narrative as it cannot present life with order, thereby resulting in narrative disorder which gives way to a personal and cultural dislike for such stories as it becomes unbearable to witness the utter chaos of one's life. Arthur W Frank reflects the hegemonic structure into play where restitution narratives are accepted and welcomed by readers as the wish to decode only aspects of remedy, progression, breakthrough and improvement of the health in the narratives. This only results in the complete dominant hegemonic reading position the reading community takes with total

disregard for chaos narratives and Arthur W Frank presents a de-centered notion of illness in the following lines:

Neitzche suffered from undiagnosed chronic ailments, including debilitating headaches. He wrote, "I have given a name to my pain, and call it "dog". Neitzche describes his pain as having dog-like attributes of being faithful, obtrusive, shameless, entertaining and clever. "I can scold it and vent my bad mood on it, as others do with their dogs, servants and wives". (Frank, 116).

Illness and health are processes that are conceived in different ways. A human being is considered as an entity where he finds interconnectedness of his mind, body and the world. But the Cartesian concept of mind-body split has affected the ways in which illness has been practically observed. Pain is conceptualized as a private and individual experience and the diagnosis of a patient is done without the consideration of his mental well-being. The ill person continues to live in pain and the individual world is tremendously disrupted by suffering a stigma as people have a negative perspective of illness leaving them the marginalized 'other'. Such stereotypes also affect people's perception of looking at pathographies or illness narratives in a depressing way. In analyzing the broad field of Medical humanities, one can come to a premise that a society can be classified on Marxian model as people with good health on the superstructure and with ill health at the base. The Gramscian concept of hegemony is clearly reflected in the narratives of pathographies as it represents their dehumanized existence and gives too much pressure on them for restoration of health as contemporary culture views health as one having a normal condition.

The Gramscian concept of 'hegemony' can help us navigate through our understanding of Arthur W Frank's *The Wounded Storyteller* as it clearly helps us in positioning the illness narratives against the dominant culturally established narratives in matters of medicine and literature. The division of a society on the basis of economic relations by Marx into base and superstructure is modified by Antonio Gramsci. He divides the society on the basis of culture and further splits the superstructure into two, namely, the political society that is dominated by supremacy and civil society that exercises hegemony of intellectual and moral leadership in a society. The political society stands as oppressive forces in the form of government, police and legal systems and the civil society dominated all institutions that construct public opinion which includes education, arts, religion and institutions of all kinds that influence public opinion. Stuart Hall, a cultural theorist, addresses the concept of hegemony and culture studies on the basis of the Gramscian model. Hall is one of the theorists who laid the importance on the theory of encoding and decoding a text. Ant text or narrative is a product of culture and the meanings embedded in the text is encoded and decoded by its influence, He says,

Primarily, culture is concerned with the production and exchange of meanings-between the members of a society or a group. To say that two people belong to a same culture

is to say that they interpret world in roughly the same ways and can express themselves, their thought and feelings about the world in ways that will be understood by each other. (Hall 2)

Stuart Hall argues that the reader or listener when interpreting a text takes three positions, namely, the dominant/hegemonic position, the negotiated position and the oppositional position. When the reader takes the dominant/hegemonic position, he accepts and decodes the meaning of a text set by assumptions and beliefs of the dominant/hegemonic narratives encoded in the text who share similar cultural biases. The reader who takes on the negotiated position exhibits a combination of adaptive and oppositional standpoints and decodes the meaning in a text to suit his own beliefs and interests. A reader who takes on the oppositional position rejects and stands directly oppositional to the dominant narratives encoded in the text. Arthur W. Frank's *The Wounded Storyteller* analyzed from the cultural lens of Stuart Hall clearly expresses the position of readers who operate with a cultural bias in decoding the illness experience of patients by placing them as the marginalized 'other' in a society driven by values of health and well-being.

Arthur W Frank in his *The Wounded Storyteller* emphasizes the thought that:

Sack's chaos has its macrocosmic analogue when society looks at people in chaos and cannot see them as a social body. The difference is that Sacks takes it as his problem to reclaim his leg: society often attributes the problems to these 'others' themselves. (Frank, 113)

Conclusion: The modern day society cannot look at people in chaos as belonging to their social body. The very poor and the very sick have taken the marginalized positions in the society and are taken as the 'other'. It denies Chaos and the chaotic bodies continue to feel more depressed. A holocaust witness, a person who goes through recurrence after recurrence of cancer or a man who has been amputated of his leg continue to live a dehumanized life and their narratives continually fade into oblivion as chaos stories are generally not desirable to the readers. The narrators of chaos stories can only be helped out if they can have witnesses to their stories. A reader should understand not to transcend or reject chaos but to accept it before new beginnings can be built or new stories can be constructed. Arthur W Frank's pathography decenters the hegemonic cultural notions attached to illness and the dominant reading position taken by readers which is reflected in the following lines:

The need to honor Chaos stories is both moral and cultural. Until the Chaos narrative can be honored the world in all its possibilities is being denied. To deny a Chaos story is to deny the person telling the story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathetic relations of care. The chaotic body is disabled with respect to entering relationships of care; as suggested above, it cannot tell enough of its own story to formulate its needs and ask for help; often it cannot even accept help when it is offered. (Frank, 109-110).

In exploring the pathography of Arthur W Frank's *The Wounded Storyteller*, through the lens of Cultural theory it is important to understand that ill people need to be regarded by our own culture not as victims but as heroes of their own stories. The wounded hero through his stories, by romanticizing his illness, provides an antidote to the pretense of lives led by people reminding them that some situations in life cannot be risen above as their lives bear testimony to this philosophy of life. It also reflects a contemporaneous understanding of people's experiences and explores the societal anxieties towards reading illness stories. It is necessary to reinforce an affirmative perspective towards the patients through diligent reading to understand the dichotomies of life and death.

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