Chapter One

Introduction: Illness, Healing, Narrative

Chapter Plan

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This dissertation focuses on patient, doctor and public health narratives in the late twentieth century in India. This study will argue that disease is performed in narrative,
and may be read as organized around interventions in two key domains – the individual and the social (epidemics, however, are outside the scope of this study). The thesis moves from examining performances of illness and the healing process at the level of the individual to the performance at the level of the social/collective.

*My dissertation argues that narrative “accounts” of illness in (i) doctor memoirs (ii) patient memoirs and (iii) the medical documentary, plot the emergence of “socialized” identities for the individuals whose alteration through disease and treatment they seek to represent. In doctor and patient memoirs this narrative ordering of illness experience and its treatment takes the form of a medical *Bildungsroman*, mapping the “growth” and social integration of an individual (doctor or patient) through the condition of illness and healing. The medical documentary makes explicit the presence of disease in the individual body and reimagines this body socially through a sentimental narrative that emphasizes a shared vulnerability to disease at the level of the individual, filial and social/communal.*

This project will examine discourses of health, illness and medicine in contemporary public culture in India. Health and medicine are matters of public culture as well as popular culture. They encode power relations, questions of narrative method and stereotyping – and therefore might be profitably examined for language, discourse and narrative strategies in the Humanities. Since Humanities is defined as “all things that constitute the human”, and medicine (with attendant conditions of health, sickness, cure) is central to the very idea of the human, it is necessary, I believe, to study discourses of health, illness and medicine to examine what forms of the “human” emerge, thus making health and medicine subjects for the “Humanities”. Scholars of public culture are interested in the process through which shared meaning is negotiated among a diverse
group of individuals. Arjun Appadurai and Carol A. Breckenridge argue that the term “public culture” allows us to hypothesize a zone of cultural debate. “This zone”, they argue, “may be characterized as an arena where other types, forms and domains of culture are encountering, interrogating and contesting each other in new and unexpected ways” (6). Concepts of “disease”, “illness”, “sickness” and “health” need to be differentiated in order to make clear the varying roles of the individual, the medical practitioner and society. “Disease” can be differentiated from “illness”, in that it lies within the domain of scientific medicine and the medical practitioner, while “illness” is understood as the individual’s “experience”. “Sickness” is what society attributes to an individual who perceives himself/herself as ill and who is identified as having a “disease” by a medical professional. Moreover, each of these terms, validates action in its respective spheres. The medical professional, therefore, is responsible for identification, discovery and treatment of disease. Individuals who are ill are required to narrate their experience of illness and seek care. The duties and rights of an ailing individual are a social responsibility (“Disease” 407). Narratives of disease, in other words, are a fit subject for a Humanities project, because these narratives construct subjects and subjectivities through languages of representation.

Every culture frames disease, health, illness and cure in certain ways. Thus, the biological experience of a condition is interpreted within a framework that is not only biological, but cultural. Thus “disease”, as we in non-biomedical terms understand it, is the intersection of a physical-material condition and a discourse in which the meanings of this condition are interpreted. Bryan Turner (1997) and Paula Treichler (1998), for instance, have emphasized the discursive and material domains of disease, by combining the notions that disease is a language (Treichler for instance, defines AIDS as an
“epidemic of signification” (11)), the body is a representation and medicine is a political practice. This cultural framework of interpretation requires representation or narrative. I argue in this dissertation that narratives of disease organize our perception of various aspects of the “reality” of disease. These “narratives” are informed by and inform a “cultural imaginary” framed around disease that governs our interpretation of the “illness experience”. This cultural imaginary that “frames” definitions, perceptions and information about disease, is already in place via State authorized medical and public health discourse, fictions about disease and epidemics and reports on “scientific” research about disease in the popular domain. I will return to contemporary illustrations of the “cultural imaginary” surrounding disease in section IV of the Introduction. Doctor memoirs, patient memoirs and public health discourse, foreground the undeniable materiality of disease (in terms of pain, bodily decay, disruption) while simultaneously contributing to knowledge about the true “nature” of disease. Disease narratives thus convey the experience of illness or the “reality” of disease, through certain modes that in turn enable the construction of particular images of biomedicine, the body and the pathogen.

The “real” threat posed by the pathogen and the “experience” of illness, are interpreted within the frames of recoverability, science-as-cure, the possibility of building a “robust” immunity, the “heroic” individual battling an “invading” viral enemy that constitutes the cultural imaginary surrounding disease. This cultural imaginary thus enables a shared grammar or vocabulary, with which ideas of health, disease, medicine and the body can be articulated. An individual narrating an “experience” of illness, an institution that provides “educational information” about a disease or a doctor narrating “encounters” with viral agents, can thus deliver to the reader, the “reality” of the
powerful, yet not entirely knowable idea of disease. This is communicated through familiar sites of interpretation and identification made possible by the cultural imaginary of disease. These “familiar” narrative modes, like the materiality of an illness (physical symptoms, pain, bodily decay, rigorous treatment regiments), combine with the “individual’s” particularized reiteration of his/her actual “experience” to create the “truth” or “reality” of disease. A viral agent or pathogen is thus described as the “other” and the doctor and the medical institution are seen as “redemptive” for the individual, who is “expected” to “recover” normalcy, because the frame of interpretation for these narratives defines them similarly. The material and the discursive realms here combine to influence our “perception” of disease in these “texts”, by bringing together an individual’s “facts” about disease (defined within the frames of medical science in the form of lab tests, reports and scans, a definitive “test” to determine the presence of disease) and his/her experience of medical treatment (organized in the form of a “stoic”, “resilient” patient committed to the cause of “recovering”, or a doctor committed to the “improvement” of medical practice, yet bounded within the discursive realm of medical “care” and “cure”).

This dissertation will study the modes of representing illness/disease manifest in popular, non-fictional narratives of/about disease/illness in the late twentieth century in India. To this end, I will examine patient memoirs and physician memoirs written by Indians (both residents and diaspora) and medical documentaries produced and disseminated by the Films Division, India. The doctor memoirs I will look at are Sandeep Jauhar’s *Intern: A Doctor’s Initiation* (2008), Atul Gawande’s *Complications: Notes From the Life of a Young Surgeon* (2002), Abraham Verghese’s *My Own Country* (1995) and Noshir H. Antia’s *A Life of Change: The Autobiography of a Doctor* (2009),

This study is organized into seven chapters. The first is the Introduction, comprising five main sections. I will return subsequently in the Introduction to a summary of the remaining chapters of the dissertation. The first section of the Introduction is dedicated to examining the conceptual and theoretical framework of this study. The second section will briefly survey the domains of Medical Humanities and Narrative Medicine, within which this project is largely located. The third section of the Introduction provides a brief summary of and outlines the relevant contexts for my primary texts. The fourth section will elaborate the rationale and scope of the project,
while the fifth section details the organization of the thesis in addition to offering a brief summary of the ensuing chapters. Fictional representations of disease/illness and fiction written by doctors and patients however, are outside the purview of this dissertation.

Section I: Narrating Sickness and Healing

The act of recording an experience of sickness and healing participates in several genres and media. The following section will detail the various theoretical frames and concepts that underpin this study of an individual’s ordering of an experience of illness. I will begin by focusing on theories surrounding various genres/modes of articulating a story of the “self”, namely, the autobiography, memoir, testimonio, self-help literature, the Bildungsroman and the documentary. I will then move on to the theoretical frames that inform the representation of illness and disease manifest in the major modes under study in this dissertation: the medical Bildungsroman and the medical documentary. Subsequently, this section will examine theories of “narrating” or “storying” an experience of illness and healing. I will also detail theories of “voice” and “agency” that underpin the arguments made in this dissertation, about the concretizing of “agency” in the acquiring of a particular kind of “voice” by narrators in the medical Bildungsroman. Finally, this section will delineate theories of social and public “identity” formation that contextualize the “development/transformation”, and eventual “socialization”, performed by narrators in the medical Bildungsroman and visualized in the medical documentary.
(a) Genres/modes of Representing the “Self”

(i) Autobiography

Several of the texts studied in this dissertation are suggestively titled to indicate the “truth” inherent in the experiences/stories narrated therein. Some examples include the physician autobiographies – Sandeep Jauhar’s *Intern: A Doctor’s Initiation* and Noshir Antia’s *A Life of Change: The Autobiography of a Doctor*, Anita Jayadevan’s patient memoir titled *Malicious Medicine: My Experience with Fraud and Falsehood in Infertility Clinics* and the medical documentaries about Glaucoma, H1N1 Flu and Tuberculosis titled *Glaucoma – A Race to Blindness*, *H1N1 Flu: Few Facts* and *Your Enemy-TB*. These texts insinuate a certain “authoritative” experience and claim to clarify “facts”, construct notions of “falsehood” (of medical science), “enmity” (against the pathogen) and the “actualization” of disease (“racing” towards blindness). They raise questions thus, about “truth telling” and “authority” that can be productively studied via theories of non-fictional forms, and their appeal to readers and authors as a mode of accessing the “truth” about a particular experience. As Sidonie Smith and Julia Watson have argued in their essay, “The Trouble With Autobiography: Cautionary Notes for Narrative Theorists”, writers often subvert a fiction/non-fiction distinction to interrogate the dominant modes of truth-telling and self-representation (363). The narrators of patient-memoirs and doctor memoirs relate the story of their “heroic” battles against disease, empowered by the textual authority afforded by the autobiographical form. In addition, in his examination of medical autobiography in “Physician Autobiography: Narrative and the Social History of Medicine”, Donald Pollock asserts that the life story of an individual is only worth recounting if it somehow deviates from the ordinary and commonplace (109). Pollock argues for a “professional conscience” that novice
physicians give voice to in physicians training tales (123). Physician autobiographies, Pollock argues, sometimes offer a kind of “projective screen” that helps their authors cast uncertainties and anxieties regarding bureaucracy and medical science (124). In recounting their days of medical education/training as “novices”, the doctor is able in his autobiography, to articulate a critique of medical practice and express uncertainties about the effectiveness and universality of medical science. The autobiography and other non-fictional forms also give rise to questions of cultural/professional authority, a point I will return to later in the section on “Voice and Agency”. For now, we can move on to a discussion of the “pact of listening”, or the conditional nature of reading/writing non-fictional forms and their engagement with the reader’s “present”, using the testimony and the memoir as illustrations.

(ii) Memoir and Testimony

As argued by Nancy Miller and Jason Tougaw in their *Extremities: Trauma, Testimony and Community*, a testimony cannot take place in isolation and is contingent on a “response” from the listener/reader. A testimony tries to bridge the gap between an individual’s suffering and a community of listeners. This “contract of listening” involves an empathetic response on the part of the listener/reader, which is palliative for the witness/speaker (11). Working with ACT UP’s slogan “Silence=Death”, Jason Tougaw argues that the subjects of AIDS memoirs are in a state of “crisis” and write in order to survive and to put an end to the epidemic. The AIDS memoirist, however, rarely lives to see the effects of his/her literary act of writing, despite the promise of ACT UP’s slogan, “Silence=Death”. He/she thus generally tends to abandon the act of writing. Tougaw argues that memoirists’ abandonment of writing does not take away the power of their memoir as a “speech act”, as such an “act” speaks for a collective and endeavours to
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disseminate the “story” of this collective, to prevent the recurrence of the historical conditions that led to trauma for the collective. AIDS, however, occupies a unique position within the above formulation, as the conditions which led to the writing of the memoir continue to exist in the reader’s present. This has led to the reconfiguration of gay discourse and gay communities, as the memoir itself is a reminder of the grim conditions that led to its production (175).

The narrating “self” in several of the texts under study are a reminder of the conditions that led to the literary production of these texts – doctor’s experiences with the “fallibility” of medical science and incurable diseases, patients’ experiences of chronic/incurable illness and its management at home and the medical documentary’s construction of a “vulnerable” individual whose immunity can easily be “compromised”. The “reality” of disease and the “difficulties” in the practice and execution of “healing” described in these texts, inhabits the “present” of readers and the conditions that led to its development are unresolved, thereby threatening the “self” created by the narrator.

It would also be useful at this juncture, to examine doctor and patient narratives in the light of a genre of literature that also makes powerful claims to “truth-telling”, the testimonio. John Beverly, in his “The Margin at the Centre: On Testimonio (Testimonial Narrative)”, defines the testimonio as “a novel or novella-length narrative in book or pamphlet form, told in the first person by a narrator who is also the real protagonist or witness to the events he/she recounts, and whose unit of narration is usually a “life” or significant life experience” (93). Unlike the novel, Beverly argues, a testimonio is distinguished by “sincerity” rather than literariness. Moreover, in the testimonio, narration is situated as involving “an urgency to communicate, a problem of repression, poverty, subalternity, imprisonment, struggle for survival, implicated in the act of
narration itself” (94) The narrators of doctor and patient memoirs do not strive for “literariness”, rather, they seek to communicate “problems” and “anxieties” about the nature of medical practice and articulate a struggle for survival (against illness, struggling to “become” experts in the practice of medicine) that is implied in their very act of narrating. Patients recounting their experience of illness and doctor’s accounts of treating (as professional) and witnessing (as novice) treatment of illness, constitute a more depoliticized articulation of the testimonio. In such a case, as Beverly defines it, “testimonio gives voice in literature to a previously “voiceless”, anonymous, collective popular-democratic subject, the pueblo or “people”, but in such a way that the intellectual or professional, usually of bourgeois or petty bourgeois background, is interpellated as being part of, and dependent on, the “people” without at the same time losing his or her identity as an intellectual” (98). Doctor and patient memoirs thus, suggest an appropriate ethical and political response, while retaining their identity as “professional” or “ethical experts” in a society. These memoirs speak for a collective (patients usually place themselves, however briefly, within a “society of illness”), by recounting stories of other patients met at visits to the clinic or by explicitly situating the purpose of narration as one that is to “help” or stand as testimony to “others” who have suffered silently. Although doctors similarly explicitly place themselves within “the medical profession”, speaking on behalf of an “imperfect science” as well as its powerless “subjects” (patients), their “authorial” function is not erased. Unlike the classic instances of the testimonio genre, which is a “fundamentally democratic and egalitarian form of narrative in the sense that it implies that any life so narrated can have a kind of representational value” (96), doctor and patient narratives foreground the “authorial” function by “setting apart” their narrators from “others” in the community. I will now move on to a discussion of the
documentary, as another mode of “authoritatively” and “objectively” representing the “truth” about the prevalence of disease and the experience of illness.

**(iii) Documentary**

Writing about the etymology of “documentary” – it derives from “document” which means “teaching, instruction” – Catherine Belling in her “Reading The Operation: Television, Realism and the Possession of Medical Knowledge” argues that the documentary attempts to “teach” its viewer and towards this end, the medium assumes an inequality between the knowledge possessed by its (assumed) lay viewer and the knowledge that it (the documentary) represents (15). The Films Division documentaries under study in this dissertation, thus address a mass audience and attempt to “teach” them about the common threats to their health and the various avenues for treatment that are available to those infected through the advances of modern medicine. The documentary, however, I argue, is also effective on account of its ability to “narrativize” the “event” of illness through elements that are distinctly unscientific in their particularized and subjective rendering. As Michael Renov has argued, non-fiction films may contain numerous fictive elements and thus fictional and non-fictional forms of films are mutually constitutive. These are “moments”, Renov argues, “at which a presumably objective representation of the world encounters the necessity of creative intervention” (2). In “teaching” their viewers “objectively” about the many dangers to their normal/healthy bodies and lives, however, these documentaries also have to inevitably “creatively” visualize and narrate for their audiences, what constitutes a “healthy” and consequently “normal” body and what conditions/factors lead to this “healthy” body’s failing under siege by illness. I will return to questions of “narrativizing” or “storying” disease/illness subsequently in this section.
The documentary derives its “authority” to teach or instruct, from the popular associations built into the camera’s ability to “record” rather than “interpret” and the non-fiction film’s (as the documentary is sometimes studied) preferred focus or domain being the “real” as opposed to its “fictional” counterpart. As Brian Winston has argued in his “The Documentary Film as Scientific Inscription”, despite filmmakers’ denials of objectivity off-screen or even their assertions to presenting a subjective viewpoint onscreen, their work is both contained and contradicted by science’s powerful cultural contexts (41). Owing to popular belief in the camera’s scientifically precise ability to “record”, the documentary, Winston argues, cannot shake off the “evidential” and the “scientific” because such contexts are already inbuilt “in the cinematographic apparatus” (41). Just as the testimony requires a “response” from the reader/listener and cannot take place in isolation, the documentary too is contingent upon viewers’ “perceptions”. In his Documentary, Dave Saunders has argued that what partly makes a film a “documentary”, is the way it is watched by a spectator or viewer. “The way we look at, react to, and anticipate a film”, he argues, “crucially has a bearing on how “real” we perceive it to be” (14). Despite the “authority” invested in the narrators of non-fiction genres like the documentary, testimonio, memoir and autobiography, these “narratives” also expressly rely on the “accounts” of others to piece together the origins of their own “self”. A narrative recounting of an experience of illness thus relies on caregiver’s accounts of the period of illness, for “moments” that lie beyond the scope of memory and reconstruction. In addition, these narratives also rely on mainstream ideas about the experience of illness and “resilience” of the self that are informed by fictions about disease, state authorized medical discourse and popular media reportage. The next section will thus examine the
genre of self-help literature and “relating narratives”, to theoretically contextualize patients’ and caregivers’ accounts of illness.

(iv) Self-Help Literature and “Relating Narratives”

This dissertation studies patient memoirs or patients’ accounts of an experience of illness that often take the form of self-help literature. These texts typically offer information and advisory for the reader, about various aspects of the particular illness detailed therein, in addition to “performing” an “improvement” of the ailing self. In her study of self-help literature in “All About Me, I Mean, You: The Trouble With Narrative Authority in Self-Help Literature”, Louise Woodstock identifies the elision of the influence of social factors in the narration of an “individual” story of success (325). Authors of self-help books, Woodstock argues, whose narrative authority proceeds from their “articulation of similarity” with the reader, place considerable responsibility and power on the individual, while denying the influence of socially circulating narratives of positive thinking and progress (325).

Lisa Diedrich also suggests in her Treatments: Language, Politics and the Culture of Illness, via Barbara Ehrenreich’s study of “brightsiding ideology” at work within “mainstream breast-cancer culture”, that narrators working within this “mainstream culture”, elide the structural and environmental influences on the acquisition of cancer and focus instead on individual responsibility, risk and management through early detection (51). “Brightsiding” involves a relentlessly positive attitude about cancer, where it is seen not as a dreadful disease that needs to be prevented but as an opportunity for creatively transforming the self (51). Treatment, in such narratives, is seen as the source of pain and suffering, rather than the disease itself. Patient-narrators similarly perform a selective process of affiliation, where only some qualities possessed by the
narrator’s self are rendered “identifiable”, thereby “learning” to eliminate aspects of the self that do not qualify as worthy of “survival”. As Diedrich and Woodstock have argued, these narratives of “progress” and “improvement” possess an aspirational quality for their readers and as such attempt to “teach” the circumscribing of an experience of illness, through the lens of “progress” and “improvement” with an exclusive reliance on the self.

As argued earlier in this section, in addition to a concretizing of narrators’ “authority”, these non-fictional accounts of illness experience also rely on the accounts of others to recreate their “origins”. Anne Whitehead in her analysis of “care” and “caregiving” relations in “Writing With Care: Kazuo Ishiguro’s Never Let Me Go”, defines “relating narratives”, a term that she borrows from Adriana Cavarero, by emphasizing their origin in a desire we all have “to tell others who we are” (68). This “narrative of ourselves” Whitehead argues via Cavarero, is essentially a “relational” one since in order to narrate one’s story from the beginning, one needs to rely on the information others have about our origins or birth (68). Similarly, writing about “relating” acts of representation in his “Metamorphosis: Defending the Human”, Michael Rowe examines his role as caregiver during his son’s struggle with ulcerative colitis (a form of inflammatory bowel disease). Rowe underscores the importance of the caregiver, in representing the “prior” self of the patient transformed by illness. He argues that the “humanity” and “humane” treatment of the patient in the hospital bed, now reduced to someone other than himself on account of illness, is dependent upon the caregiver’s memory and representation of a past/normal/recognizable self of the patient in the space of treatment. Rowe, for instance, recalls how he and his wife individualize the space of the hospital room – they tape the “get well soon” messages that his son received from family members, along with pictures of him from a time prior to his hospitalization next
to the medical charts that narrate the progress and state of his illness (276). Personal artefacts (the “get well soon” cards and photographs of a time of “normalcy” and “familiarity”) here serve to close the gap between the patient transformed by illness and the “person” he/she was and still is – linked to a network of family and friends and the world at large. Rowe is here drawing attention to the significance of the caregiver’s memory and the narrativizing of his/her role for the “humanity” and “personhood” of the patient.

The patient-narrator, I argue, empathetically reimagines his/period of dependency and the consequent burden on a caregiver. This empathetic reimagining of the caregiver’s “silent” suffering, is the only access the patient-narrator has to his/her period of transformation – a period of dependency, of feeling not quite like oneself – and thus is essential for his/her own recognizability as a “person”/ “individual”. The patient-narrator becomes recognizable and “familiar” for the reader, like Rowe’s son does at his hospital once his caregivers begin to represent his prior self for the doctors and nurses, through his/her empathetic reconstruction of the time when he/she was cared for, represented, in turn made “familiar” for others. I will now move on to a discussion of the Bildungsroman or the coming-of-age novel, of central importance to the texts under study in this dissertation. While the Bildungsroman is traditionally a fictional mode, it has a functional significance for the narrators studied here, with respect to enabling the articulation of an “emerging” self and its progress towards socialization through a condition of illness and/or healing. This next section will detail Franco Moretti’s (1987) examination of the Bildungsroman as a novelistic tradition in Europe and Joseph Slaughter’s (1997) reconfiguring of this genre, in terms of “narratability” and “human rights”. The next section will thus contextualize this study of doctor and patient memoirs as illustrations of
the “medical Bildungsroman”, a cultural, non-fictional instance of the classical, primarily novelistic mode.

(v) The Bildungsroman

Franco Moretti emphasizes the significance of “youth” as a symbol in the Bildungsroman in his study of the genre, The Way of the World: The Bildungsroman in European Culture. Youth is chosen to represent modernity as its “essence” since modernity “perceives the experience piled up in tradition as a useless dead-weight, and therefore can no longer feel represented by maturity, and still less by old age” (5). Youth in the Bildungsroman thus functions as a specific material sign that is characterized by its ability to accentuate the instability and dynamism of modernity. However, this novelistic “symbolizing” of youth as similar to modernity in its formlessness, instability and “protean elusiveness”, could potentially destroy youth itself as a “form”. To survive successfully as a form therefore, youth in the Bildungsroman has to be endowed with a feature that is opposed to those characterizing modernity – it is thus circumscribed, perceived as having to “end”, as a period that does not last forever. Youth thus allows the establishment of a formal constraint on the depiction of modernity. Modernity is thus “humanized” and integrated into our intellectual and emotional system, rather than being seen as it usually is – a bombarding, hostile force that threatens with an “excess of stimuli”.

The doctor’s status as “professional” is thus “humanised” in the medical Bildungsroman and acquires meaning precisely through the circumscribing or elision of the “novice”, “filial” self. The “novice” self of the doctor, during the period of medical education, symbolizes “youth” that must be overcome/circumscribed to allow for the development of the “expert”/ “Professional” self. The doctor/narrator is socialized or
integrated into a community, by transcending his/her “passively” acquired inheritance (in terms of knowledge acquired from the medical institution and family) to become a “professional”. As a “professional”, the doctor reflects this emergence, but also alters the scope and degree of transformation and socialization for the doctor protagonist in the *Bildungsroman* in new and unanticipated ways. The patient narrating an experience of illness similarly elides or circumscribes a self “prior” to the onset of illness, to construct a “stoic” resilient self who was always already *capable* of survival. The patient is socialized in the medical *Bildungsroman* through the performance of “ethical expertise”, where he/she is embedded in a social network of disease literacy and “learns” a new skill and temperament occasioned by illness. “Stoicism” and the “capacity” to survive mark the patient’s “growth” from the period of illness, seen as the “youthful” or passive state where the patient’s identity is equated with illness alone. As “ethical expert”, the patient is able to insinuate himself/herself into a community for whom he/she “speaks” and with whom he/she *shares* the experience and knowledge gained during illness. Joseph Slaughter suggests via Adenos Addis in his “A Question of Narration: The Voice in International Human Rights Law” that human rights can be productively reconceived in terms of narratability (412). He argues that in the modern *Bildungsroman*, any restriction to “liberty, property, security and resistance to oppression” tend to limit the individual’s ability to attain fixity for his/her “self”. This fixity of the modern hero in the *Bildungsroman* is dependent upon his/her ability to narrate his/her story (412). Through the articulation of a particular kind of voice that emphasizes the social and draws upon the textual and cultural authority of the author, doctors and patients in the medical *Bildungsroman* are able to narrate their “story” of heroic self-discovery to attain fixity for the “self” thus created. The *Bildungsroman* thus gives rise to questions of voice, narration
and agency. The following section will examine the “narrativizing” or “storying” of illness experience and disease and I will return subsequently to questions of voice and agency.

(b) Narrating/“Storying” Illness/Disease

This section will examine the theoretical frameworks that enable us to examine the “narration” or “plotting” of a “story” of experiencing/healing illness and disease.

In her *Narratology: An Introduction*, Susan Onega via Mieke Bal, identifies a “story” as that level of a narrative which functions as the “signified” of a narrative text. In its turn, Bal argues, a story signifies a fabula (6). Building on Bal’s formulation, Susan Onega argues that the “story” is thus a linguistic construct, a cognitive scheme of events that could, in turn, give rise to a number of texts (8). The “stories” negotiated by the narrators of patient and doctor memoirs, are crucial to the construction of their “social self”. Moreover, these narrators articulate their story in what can be seen as a “narrative society”. Building on Hayden White’s formulation of histories, events and lives being made to conform to story “types”, James Dawes in “Narrating Disease: AIDS, Consent, and the Ethics of Representation”, argues that the presentation of disease as a “story” similarly exploits linear narration and causality as a means of “restoring understanding and thereby alleviating the damage of confusion” (39). Disease as a story and therefore as a finished and complete event, serves the purpose of an apparently “unified” self that doctor-narrators construct in what Dawes terms a “narrative society” (38). The narrative society, for Dawes, conceptualizes itself and people as “stories” and as “narrative”, rather than through narrative. The doctor-narrator in the medical *Bildungsroman* emphasizes the importance of “story” with references to the therapeutic power of narrating and integrates
several “stories”, most importantly those of patients, to present a unified, social “self” that is attentive to the ethical dimensions of the medical narrative. “Narrative” can thus be a productive means of conceptualizing individual and collective identities.

In a different context, writing about the ways in which members/participants in the online project Wikipedia construct and understand themselves as a “community”, Christian Penzold emphasizes the significance of studying the “symbolic”, rather than the “structural” constitution of communities (705). The doctor-narrator frames in his memoir, an ethos community, whose membership is governed by this narrator’s self-understanding and self-description. Pentzold has identified the ethos community as an instance of community formation through a shared negotiation of the “meaning” or “understanding” of community. In such a community, “communication” is of primary importance and actors/members of the group are themselves responsible for the production and sustenance of a commonality of structure, meaning and culture. The ethos community for Pentzold is defined as an “open body” which does not have any clearly demarcated boundaries and is a “group of concepts” linked around the understanding of the term “community”. The members of this community, Pentzold argues, are governed by a voluntary interest in participation but also the commitment to “a set of norms, behavioural standards and attitudes – by sharing its ethos” (712). The doctor-narrator’s ethos community is thus formed in his/her articulation of a particular set of norms and his/her designation of “productive” and “activist” patient stories as “ideal” responses to illness. I will return to issues of “normative”, “vulnerable” and “pathologized” identities constructed by disease/illness narratives in a subsequent section on social identity. For now, we can move on to questions about the centrality of narrating an experience of
illness/healing and its link to the “difficulty” or “impossibility” of visualizing disease and bodily interiors.

The centrality of “narrating” or “storying” an experience of illness is related to its ability to “unify” the narrating subject’s “self”, seen to be threatened/disrupted by the onset of illness. Michael Bury in his “Chronic illness as biographical disruption” has made a case for illness constituting “biographical disruption”. In my study of the medical Bildungsroman however, I am interested in how patients construct a “social” identity that is not defined by illness alone. The “disruption” brought on by illness is seen not as a “break” or “rupture” in the individual’s biography, but as an occasion for the articulation of a “new” identity. This “new” identity in the patient memoir is seen to have origins in the person’s “self” prior to the onset of illness. “Interruption” by illness is thereby elided and the ill-self is refigured as being always already characterized by strength and resilience, typified by the “new” identity articulated in the patient memoir. “Narrating” an experience of illness also assumes centrality on account of the difficulty inherent in representing/remembering the body at a moment of extreme suffering. As Arthur Frank has noted in his “The Rhetoric of Self-Change: Illness Experience as Narrative Author”, the authority and appeal of the illness narrative lies in the belief that “truth” is what is produced when a body is at the extremes of suffering (48). Illness narratives, argues Frank, are an important means of studying how illness is socially constructed as a rhetorically bounded and discursively formulated phenomenon (“The Rhetoric of Self-Change” 41). “Narrating” or “storying” an experience of illness is however also significant, on account of the difficulty or impossibility inherent in directly apprehending bodily interiors and accurately “visualizing” disease and its onset.
Not only do illness narratives present an “extreme test case”, in the words of Rimmon-Kenan, because of “the embodied nature of both continuity and disruption in them” (“What Can Narrative Theory Learn from Illness Narratives?” 244), but they also seek to articulate and interpret the visceral body. The visceral body is only known to the patient-narrator via biomedical tools of visualization, argues Belling in her “Narrating Oncogenesis: The Problem of Telling When Cancer Begins”, a study of the “difficulty” in ascertaining the precise “onset” of cancer. The visceral body, Belling states, is not “human”. In order to narrate this visceral body, she argues, “we must first imagine and humanize them, constructing the subjective habitation that marks the material of the body as place” (233). Examining scientific narratives about the origin of cancer, Belling argues that such narratives rely on “the complete effacement of the human and the partial anthropomorphosis of the renegade cell” (237). Patients thus creatively reimagine their bodily interiors and the progress of illness/treatment in their memoirs. In his study of the “culture of dissection” in the Early-Modern period, The Body Emblazoned, Jonathan Sawday illustrates this “individuality” or the “subjectivity” of bodily interiors, through a detailing of “the experience of the body” historically. He argues that although the interior of the body may carry signs of its “individuality” these “interior” signs cannot be observed in ourselves and can only rarely be discerned in others’ bodies. It is this impossibility of observing our “unique” bodily interiors, Sawday argues, that makes the “exploring” of other bodies so captivating. We explore and journey through other bodies in the hope/fear that these “others” will be like “us” (7-8). Despite the impossibility of “knowing” our bodily interior and directly experiencing it, this interior is nonetheless relentlessy interpreted via various means of representation – from the early anatomists’ “maps” of the body and the creative engagement with bodily interiority in literary texts in
the seventeenth century to modern day imaging technologies like the X-ray and the MRI. This relentless interpretation or “deducing” of the interior of the body, Sawday argues, is what gives rise to the drive to understand the body through “representation” (7). The “body” is thus simultaneously represented in a subjective rendering of an experience of illness/healing.

The body, as Rita Charon argues in her *Narrative Medicine: Honoring the Stories of Illness*, co-authors the story of the life that is being lived in it. The telling of a story of illness, Charon argues, is the telling of two tales simultaneously – the story of the “person” of the self and the story of the “body” of the self. The body, however, despite its materiality, communicates only through representation, which is in turn mediated by sensations and meanings that are ascribed to these sensations (87). While the body can only be “articulated” and “reimagined” via representation, illness/disease is also difficult to apprehend directly except through specific “tools” or “modes” of visualization. Kirsten Ostherr in her *Cinematic Prophylaxis: Globalization and Contagion in the Discourse of World Health*, foregrounds the crisis and anxiety about “visibility” that affects public health discourse, on account of the difficulty in the cinematic medium in “visualizing” for audiences, predominantly “invisible” pathogens (180). This struggle to visualize “invisible” pathogens, Ostherr argues, is responsible for public health cinema’s reliance on indexical and artificial modes of representation. To dispel the fear of bodily and national invasion by invisible contagions, this threat is visualized as a racially and sexually marked body with temporally and spatially distant origins. Films Division documentaries often rely on indexical modes of representation like maps that mark areas of increasing and reduced “risk” of contagion/infection, in addition to artificial modes like an animated anatomically “correct” body on which the “deviance” or “corruption”
induced by disease can be “marked” for the viewer. However, this “visualizing” or “representing” of disease in the medical documentary also gives rise to questions about the “marking” of threat on “deviant” or “pathologized” bodies, a subject I will return to in the section on social identity.

Finally, narrating a “story” of illness or healing also gives rise to questions of “agency” and “voice”. Patients and doctors writing about an experience of illness and its treatment, often articulate a critique of medical practice and exercise choice with regard to the nature of “constituting” a story of the self. As Michael Bury argues in his “Illness narratives: fact or fiction?”, illness narratives find a new voice in the face of rising scepticism against medical practices and the growing impact of degenerative and chronic illnesses (267). The “grand narrative” of biomedicine has thus given way to the patient’s right to speak, about his/her subjective experience of the “heterogeneous” character of chronic illness and its everyday management. In other words, grand narratives of biomedicine are increasingly countered, supported or even subverted by petitehistoires, or the personal stories, of the ill. As Arthur Frank has noted in his “Five Dramas of Illness”, the “drama” of a story is not only present in this story as a conflict of forces but is also enacted in the process of arriving at a story. This process includes “resisting or provisionally accepting and then rejecting other stories” (384). The medical Bildungsroman thus enacts a process of arriving at a “subjective” “story” of an experience of illness or healing. This “process” involves the exercise of agency in the “provisional acceptance” or “editorial selection” of aspects of illness and healing, to articulate a particular, “subjective” “voice” for the doctor or patient narrator. The medical Bildungsroman is thus characterized by a subjective rendering of personal stories that are made to fit, through the exercise of agency, already existing frames or models of
narration. The next section will survey the theoretical frames underpinning the examination of voice and agency in doctor and patient memoirs.

(c) Voice and Agency

An agent, as Anthony Giddens has argued, can elaborate discursively on the reasons for his/her actions. “Mastery of “I”, “me”, “you” relations, as applied reflexively in discourse”, Giddens argues, “is of key importance to the emerging competence of agents learning language” (The Giddens Reader, 94). In her Narrative Fiction: Contemporary Poetics, Rimmon-Kenon identifies a narrator, at a very minimal level, as the “agent which at the very least narrates or engages in some activity serving the needs of narration” (90). Narrators of doctor and patient memoirs are thus invested with a degree of agency in elaborating discursively about a subjective experience of illness/healing. These narrators also “creatively” transform the “self”, through a reimagining of experiences of others, the inner recesses of the body and through a visualizing of their “potential” to change. Lois McNay, in her Gender and Agency, attempts a reconfiguring of agency in terms of creativity of action. She uncovers this “creative or imaginative substrate to action”, to illuminate how action transcends its social, economic, cultural, corporeal and material context. “A creative dimension to action,” McNay argues, “is the condition of possibility of certain types of autonomous agency understood as the ability to act in an unexpected fashion or to institute new and unanticipated modes of behavior” (22). Thus the patient, rather than revert to his/her “identity” prior to disruption by illness, articulates a “new” identity about a self that has been “transformed” by illness. Physician-narrators in the medical Bildungsroman are invested with the ability to “transform” or “change” over the course of the narrative,
thereby transcending their cultural, corporeal and material contexts. The narrators of these texts are also engaged in carving out a space to “voice” a particular “story” of/response to illness and its treatment that draws upon and contributes to a certain “textual” and “cultural” authority. I return here to questions of “voice” and its engagement with/contribution to a particular textual and cultural/professional “authority” for the author/narrator.

Ananda Mitra in his “Voices of the Marginalized on the Internet: Examples from a Website for Women of South Asia”, conceptualizes voice as the acquiring of agency through which a speaker can assume the position of the “speaking agent”, in order to “produce a specific kind of voice for himself/herself” (493). In recounting their experiences of medical education (as novice practitioners of medicine during internship and residency) and subsequent, often imminent, transformation into “experts” (whose “education” now accrues independently, through “real-life” forays into treating illness and healing patients that often takes them outside their immediate “role” within the institution), the doctor-narrator in the medical Bildungsroman is able to carve out a space from which a story of heroic emergence, or a narrative account of the construction of a “social” self can be articulated. Mitra and Eric Watts suggest in their “Theorizing Cyberspace: The Idea of Voice Applied to the Internet Discourse”, that rather than conceiving of voice as an “effect of the text” or as “the property of the autonomous subject”, it can instead be viewed as a “dialogic event”, seeing it as a “phenomenon constitutive of ethical and emotional dimensions” (483). Voice is thus “public”, in that it always presumes an addressee/reader/listener and examining voice necessitates a consideration, of how rhetoric and specific acts of “public discourse” comprise the means through which a community reinvents and sustains itself (484). The doctor-narrator’s
agency in the medical *Bildungsroman*, I argue, is concretized in the voicing of *particular* narratives of patients. In their “Development of the Physician's Narrative Voice in the Medical Case History”, David H. Flood and Rhonda L. Soricelli identify the importance of finding an “appropriate narrative voice” for the case history. The case history has been criticized by Suzanne Poirier in her “Voice in the Medical Narrative” for being ethically limited in its condensed form (52). Flood and Soricelli argue for the importance of a narrative voice for the physician in the case history that can fulfil the humanistic and technological demands placed on this particular document that possesses many characteristics of a narrative (67). The doctor-narrator in the medical *Bildungsroman*, I argue, through narrating his/her “story”, attempts to find a narrative voice that unifies an otherwise fragmented experience of treating and rehabilitating illness and provides the ethical dimension otherwise missing from the medical case history. Moreover, the acquiring of agency through the articulation of a particular “voice” is also linked to questions of “authority”.

Wayne Booth argues in *The Rhetoric of Fiction* that the author exercises effective control by making clear to the reader, the “nature of the dramatic object” (200). In the case of the medical *Bildungsroman*, the doctor-narrator, through various means, makes clear to the reader how his/her experience deviates from the ordinary. As Booth argues, the author, like the doctor-narrator, makes clear the dramatic object’s nature, by giving the reader the “hard facts” and “by establishing a world of norms by relating particulars to these norms or by relating the story to general truths” (200). With respect to the realist medical narrative, Jan Marta has argued in his “Postmodernizing the Literature-and-Medicine Canon: Self-Conscious Narration, Unruly Texts, and the Viae Ruptae of Narrative Medicine”, that the particular significance of the physician-author’s narrative
authority is to establish his/her authority over the “written medical truth”. To this end, the narrative function of the patient-character is curtailed, to enforce the physician-narrator’s authority over both the primary narrative as well as the “written medical truth”. The doctor here voices in a heteroglossia and seeks to include the voices of patients as well. Heteroglossia, as Bakhtin has argued, “is another’s speech in another’s language, serving to express authorial intentions but in a refracted way. Such speech constitutes a special type of double-voiced discourse. It serves two speakers at the same time and expresses simultaneously two different intentions” (324). The doctor-narrator seeks to particularize and voice the patient’s narrative, itself already entangled in “someone else’s discourse about it” (Bakhtin 330), and renders in his own language, an individualized utterance of a patient’s story.

The doctor-narrator here seeks to overcome, in his/her voicing of the patient’s narrative, the inherent “otherness” of this narrative, to make it his own. The doctor-narrator in the medical Bildungsroman also seeks to ensure the viability of his/her role for the community/society, in articulating the story of a “growing” or “emerging” expertise. The “diagnostic agency” of the doctor-as-expert is seen to be declining and the doctor narrating a subjective experience of “learning” to practice medicine ethically and transcending his/her immediate professional/cultural role, seeks to restore this declining agency. Tom Rice has argued in his study of the politics of stethoscope ownership and display, “‘The Hallmark of a Doctor’: The Stethoscope and the Making of Medical Identity”, that there exists a discourse surrounding what he identifies as “the death of the stethoscope”. The stethoscope, Rice argues, iconic of the “ideal” doctor, who possesses a good “bedside manner”, with humanistic qualities of concern and empathy and can make an effective diagnosis relying on listening skills and similar “perceptual sensitivities”, is
seen to be jeopardized by an increasing encroachment by modern technologies. The stethoscope, Rice suggests via Alfred Gell, is “seen to hold ‘agency’ in the various ways in which it enables doctors and medical students to project and perform their respective skills, experience and competence” (288). The real threat posed by the “death of the stethoscope” thus, is to the doctor’s diagnostic agency, since this becomes widely dispersed with the introduction of technologies like echocardiography, which rely on a wider network of technicians and machines rather than on a specialized auditory skill learned and practised by the doctor. “Where the doctor becomes simply a point for the collation of test results”, Rice argues, “the value of his or her role and that of the entire profession will fall” (300).

In a different context, writing about the differences between Latin American writer Alejo Carpentier’s travel account, “On the American marvelous real” and its other metropolitan, European counterparts, ML Pratt argues in her Imperial Eyes: Travel Writing and Transculturation that the “neocolonial difference” is primarily articulated as a difference of authority, “a difference in what one is entitled to claim to know about others” (227). For the traveller from the neocolony, she argues, without book knowledge he/she is not entitled to write. European travelogue conventions generally do not require claims of unease about a lack of book knowledge about a particular destination. Travellers from the neocolony, however, commonly express uneasiness about lacking book knowledge about the place travelled to and are at ease when they recognize, from novels, for instance, names of places they are seeing. Carpentier, Pratt describes, even when surrounded by a place familiar to him from novels, still deviates from the conventions of other metropolitan travellers. He records what he is seeing, that is the “known world of Western Europe”, in “experiences of recognition” rather than in “acts of
representation” (228). Carpentier is not concerned with recreating what he saw in the mind of the reader. Rather, he records what he recognizes from sights already identified in earlier travels or from the “antecendentes literarios”. Therefore, rather than claim the European cultural authority to depict, represent or recreate what he sees, Carpentier only claims authority to “express recognition of what he has learned or been taught to know is there” (228). The doctor-narrator similarly utilizes as raw material for his narrative, what is learned during formal education and what he/she recognizes as the narrativizable particulars of individual patient narratives. The literary antecedents for the doctor-narrator comprise what he/she learns of the progress of disease in the body, but also what he/she learns from the patients’ individual, particular presentations of accounts of illness experience. Carpentier’s traveler, Pratt argues, exhibits an “uneasy insistence” on book knowledge, because of the “cultural predicament” he faces as a “peripheral intellectual”. For him, “‘real’ reality and ‘real’ history have been lived as somewhere else” and he is “a portrait of the neocolonial autodidact whose personal library is the basis for his claim to belonging in modernity” (228). The doctor-narrator, like Carpentier’s traveler, enters the narrative of the patient’s history of illness, after it has already traversed half or sometimes more of its course outside the narrative purview of the doctor-narrator. The “real” reality of the disease and its “real” history, are only accessible to the doctor-narrator in a general context, partly through his own personal library of universalized, general knowledge about the disease and in the case of the individual, particular patient, almost entirely through the patient’s own retelling to the doctor of the “story” of the onset of illness in his/her particular case. The “real” reality and the “real” history of the disease, for a time, before the patient’s entry into the hospital, have been lived somewhere else. The doctor-narrator’s agency is concretized in voicing particular narratives of patients, in recording
his “recognition” of particulars from literary “antecedents” that comprise patients’ own narratives of illness experience.

The particulars of patients’ “stories” in the medical Bildungsroman are rendered by the physician-narrator as “immutable” or “combinable” mobiles. The new doctor-body presented in the medical Bildungsroman, is interested in bringing to the centre of medical knowledge, those aspects of disease and ailing individuals that are not yet familiar, that are yet to be integrated into the corpus of information that constitutes the doctor-as-expert. The corpus of information collected through the network created by the new doctor-body generates what Bruno Latour defines as immutable and combinable mobiles. In his Science in Action, Latour defines knowledge not in opposition to “ignorance” or “belief” or even by describing the thing itself, but by regarding what he calls a whole “cycle of accumulation”. This “cycle of accumulation” for Latour, is a way of being “familiar” with “things, people and events, which are distant” (220). Once these “unfamiliar” elements that exist on the peripheries of medical knowledge are transformed in the doctor-narrator’s informational narrative, into mobile and combinable elements, they can be brought back to the centre of medical knowledge. From this centre, these peripheries, these elements that were anomalous-before-but-recognizable-now, can be dominated from afar. Latour identifies a paradox at the heart of the construction of centres – they require elements that have to be brought from far away, without bringing them in for good. This paradox is resolved, he argues, “by devising inscriptions that retain simultaneously as little and as much as possible by increasing either their mobility, stability or combinability. This paradox between presence and absence is often called information” (243). In narrativizing/bearing witness to a patient’s story of illness, the doctor-narrator engenders a cycle of accumulation that renders these “stories” stable,
mobile and combinable, so they can be brought “home” to the centre (the medical institution). In this process (technologies of representation employed by the doctor-body’s informational labour like the case history, medical “reports”), the doctor’s “story” retains not the patients’ themselves, but as much informational representation as is required to make “familiar” the pathological/abnormal unfamiliarity of their bodies and to diminish the distance between them and the “expertise” accumulated via the doctor-body at the centre.

The doctor-narrator’s “authority” over rendering patients’ stories, is also validated via the “trappings” of medical education or the “body work” performed by this narrator. The “trappings” of medical knowledge include the as-yet-unintegrated information, practice and experience required for the “novice” doctor to attain “expertise”. These “trappings”, symbolized by the “intern’s coat” and various diagnostic tools that over time become “transferrable” to the doctor-as-expert, function as “boundary objects”. This “boundary object” validates “work” and “expertise” in social worlds outside the doctor-narrator’s immediate corporeal and material contexts and allows him/her to exercise agency in these contexts/worlds. “Boundary Objects”, as defined by Susan Leigh Star and James Greisemer in their “Institutional Ecology, “Translations” and Boundary Objects: Amateurs and Professionals in Berkeley’s Museum of Vertebrate Zoology, 1907-39”, are “objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites” (393). Star and Greisemer draw attention to the importance of “boundary objects” in maintaining and developing coherence across intersecting social worlds. Though these “boundary objects” may have different meanings in different social worlds, they
nevertheless retain a structure that is common and recognizable enough in more than one of these social worlds, so as to render them easily *translatable*.

The creation and management of these “boundary objects” is informed by the “frames of interpretation” provided by medical discourse. The incorporation and circulation of these “boundary objects” in the doctor memoir is of crucial significance, since patients’ “narratives” of disease/illness emerge as they do, across diverse social groups of actors. “Boundary objects” are crucial in the establishment of a “mutual modus operandi” between actors from different social worlds. More significantly, “boundary objects” enable the creation of “scientific authority” that is invested in the hands of “entrepreneurs” who enlist “participants” or “allies” from a range of locations and “re-interpret” their interests. In this manner, the concerns/interests of the non-scientist are translated into those of the scientist, who subsequently establishes himself/herself as the gatekeeper of the mode of articulating these interests. Chapter two of this dissertation on the doctor memoir will examine how the “trappings” of medical education are governed by the doctor-narrator’s frames of interpretation as a “boundary object”, in his/her subjective detailing of the process of transformation effected from “novice” to “expert”. This chapter will examine the doctor’s insinuating of an “editorial self” and his/her exercise of agency, in re-interpreting patients’ “stories” of illness, originally “presented” by the patient in his/her own words.

Narrators of doctor and patient memoirs, as argued in the section on “Relating Narratives”, routinely incorporate the stories of “others” in rendering their own subjective “story” of their origins. Like the doctor’s incorporation of “stories” of patients and his/her exercise of agency in “re-interpreting” these “stories”, patients also routinely incorporate stories of their “carers”. Patients reconstruct caregivers’ labours, performed during the
course of illness and testify to their reorganization of the hospital space. They reconstruct carers’ efforts in making the illness-transformed narrator more “recognizable” and “familiar”, in an act of “parasitic” agency. Caregiving labour performed for an ailing other, is spatio-temporally linked to the time and space illness and thus gives rise to what I argue, is a “parasitic” mutuality of transformation. In a different context, arguing for the “global” space inhabited by the postcolonial novel, in his “The Transnational Indian Novel in English: Cultural Parasites and Postcolonial Praxis”, Pramod K. Nayar likens the relationships, exchanges and intersections between the First and the Third World represented by the postcolonial writer, to an instance of the “parasite”. Nayar suggests, via Michel Serres, that the figure of the parasite, rather than being “another” or different, in fact “plays at being the same” (forthcoming). The host, in this case, finds itself mimicking the parasite, just as the parasite in its turn changes in order to be accommodated by the host. The patient in his/her memoir instantiates a caregiver Bildungsroman, which is contingent upon the performance of a particular set of emotional attributes. This caregiver Bildungsroman is also dependent upon the acceptance of a “role” that requires a spatio-temporal inextricability with the patient-narrator’s illness. The patient-narrator’s transformations – the medical regimen, the transformation of the home and the everyday, managing the symptoms of illness – are also the caregiver’s own. The parasite here plays at “being the same”, altering itself along with the host to produce and bring to prominence only one story – that of the host. The patient-narrator in turn circumscribes the caregiver’s labour, performed in “silence”, the representation of which stands in for his/her period of transformation and dependency and renders it “familiar”. The host here changes itself to accommodate the parasite, made paradoxically more “recognisable” with its presence. However, Nayar also signals to
another crucial aspect of the parasite – that of agency and change. The parasite, Nayar argues, initiates change through the assertion of agency, consciously or unconsciously interrupting and reordering information (forthcoming). I argue that the caregiver’s “presence” in the hospital and his/her representation of the patient-narrator’s individual circumstances, filial and personal networks and multiple affiliations, aside from his/her illness-induced identity, is an act of parasitic agency. Through the reconstruction of the caregiver’s ability to negotiate the space of the hospital, by carving out an individualized inhabiting of this space that is not limited to illness and its treatment alone, the patient-narrator testifies to the initiation of change through the exercise of agency.

The above sections have examined the modes in which a “story” of the ailing/healing “self” is articulated in the medical Bildungsroman, thereby concretizing a particular, subjective “voice” and “agency” for its narrator. Narratives accounts of illness/disease and healing, however, are also responsible for constituting particular “social” identities for their narrators, constructed in opposition to “other” pathologized or “deviant” identities. The next section will examine the centrality of the “body” and “materiality” in the formation of social identity, via theories that underpin “embodied” social identities, the various “roles” performed in the enactment of social identity and the significance of “work” and “labour” in the medical Bildungsroman.

(d) Social Identity

(i) Embodied Identities: Chris Shilling, in his Body and Social Theory, has theorized the individual’s self-identity in the late modern age as an “embodied biography” (4). Bodies, Shilling posits, are seen as unfinished, in the process of becoming, as a project that is worked on by the individual as a part of his/her self-identity. The body is an unfinished
social and biological phenomenon and is “transformed” as a result of its entry into society. This is of particular significance to a patient “narrating” his/her experience of illness, since the moment of illness is also a moment of change or transformation in the person’s embodied biography. The physician and the patient’s body in the medical Bildungsroman are performed, as argued earlier, via various modes of representation. Patients creatively imagine their bodily interiors, while physicians apprehend the bodies of others through various scientific (medical imaging technologies) and non-scientific (narrativizing the particulars of patients’ stories) means of representation, as seen in the previous section. These “acts” of performing or representing the body, however, are significant in the formation of a social identity. As Suzanne Poirier has argued in her “Medical Education and the Embodied Physician”, the physician’s body and those of the patients he/she treats, is central to the work of medicine and thus, in the “preparation” of physicians, the role of the body is heightened in positioning oneself in the world (525). The physician’s “growth” into an “expert” and the circumscribing of his/her “filial” or “novice” self, is marked through a performance of “preparation”. This “preparation” is performed partly via the “trappings” of medical education as “boundary objects”, as discussed in the section on Voice and Agency. However, doctor-narrators also testify to the difficulty of translating medical knowledge, being an important aspect of the “preparation” to become an “expert”. Universalized medical knowledge, viewed as being gained passively by the “novice” self, needs to be applied to idiosyncratic, individual contexts during the practice of medicine, in order to attain “expertise”.

The physician-narrator embodies this inherent “tension” of medical practice, by “marking” the process of growth from the filial novice/trainee to the expert/professional as dramatized encounters between the physician’s body and the patient, the pathogen and
the institution. Jonathan Sawday in his *The Body Emblazoned*, signals to the trope of “heroism” implicit in the “mapping” of the body by Early-Modern anatomists like Vesalius and his followers, who were guided at the time by the belief that the human body was a miniaturized imitation of the larger cosmos. The body during this period is understood as an unexplored territory, an as yet undiscovered country that demanded from the anatomist-explorer, the same “heroic” skills demonstrated by real-life voyagers to various parts of the terrestrial globe at the time. The “triumphant” discoveries made by the explorers, cartographers, navigators and early colonialists thus become equated with the physician/anatomist’s “new” map of the body, giving rise to the “new figure” of the “scientist as heroic voyager and intrepid discoverer” (24). Like the anatomists who “come of age” during the seventeenth century, with a “new” map of the body and a “new” grammar of understanding its inner recesses, the doctor-narrator in the medical *Bildungsroman* is embodied through his/her reiteration of an individualized process of learning and practicing medicine during varying levels/stages of expertise. The doctor-narrator constructs a “heroic” identity, through a performing of his individualized process of “learning” and by “marking” or “embodying” this process as “expert”. Anne Balsamo for instance, in her “Forms of Technological Embodiment: Reading the Body in Contemporary Culture”, defines the body as a historical, cultural and social production, where production signifies both product and process. In addition to being the material embodiment of racial, ethnic and gender identities, as a product, the body is also a “staged performance of personal identity, of beauty, of health. As a process it is a way of knowing and marking the world, as well as a way of knowing and marking a self” (Balsamo 217). The doctor-narrator in the medical *Bildungsroman* is “marked”, as a “product” that is the effect of a particularized learning process. However, as discussed in
the earlier section on the *Bildungsroman*, to emerge as “expert”, the doctor-narrator has to perform an overcoming or circumscribing of the “filial” or “novice” self. The period of medical education functions as a period of “passivity” and is seen as lacking “agency”, in addition to being characterized by the difficulty of translating universal knowledge to fit particular contexts. The doctor-narrator thus performs, I argue, a kind of “cosmopolitanism”, through which he transcends the “filial” or the “novice” self to become an “expert” who can engage local and global contexts simultaneously. We can move on now to a discussion of cosmopolitanism in the medical *Bildungsroman*.

Tobias Boes has argued in his “Apprenticeship of the novel: The *Bildungsroman* and the Invention of History, ca. 1770–1820”, that the *Bildungsroman*’s process of translating historical time into a narratable and concrete pace, always contains a culturally specific component (278). I argue that the protagonist of the medical *Bildungsroman*, translates historical time via a territorialized vernacular cosmopolitanism, to circumscribe and transcend the “filial”. A cosmopolitan world view, Emily Johansen argues in her “Imagining the Global and the Rural: Rural Cosmopolitanism in Sharon Butala’s *The Garden of Eden* and Amitav Ghosh’s *The Hungry Tide*”, develops from the actual engagement with cultures and people that are different from us, rather than just an exposure to them. As Johansen defines it, “people who exhibit cosmopolitan world views see themselves as having ethical and moral responsibilities to the world and a specific local place—or even places” (3). She emphasizes the ethical and political dimensions of this definition as being characteristic of the “postcolonial-inflected vernacular cosmopolitanism” (3). Moreover, a cosmopolitan sensibility is constantly in “a state of becoming rather than being” (3). The “professional” doctor engages the global (the challenges and changing contours of
medical science) and the local (the everyday practice of medicine on individual bodies that exist at multiple cultural locations). The doctor’s intimate engagement with disease prevention and cure in plural and globalized cultural contexts, sets his “professional” self apart from the filial. The filial, understood as the doctor/narrator’s “passive” state of “being”, must attain narrative closure in the medical Bildungsroman, to allow for the representation of the “professional” cosmopolitan “state of becoming”. Like a person’s “embodied” life biography, the doctor’s “cosmopolitan” state is constantly “worked” on and is in a state of “becoming”. The narrators of the medical Bildungsroman, in the case of doctors and patients, thus constantly perform for the reader, the “work” or “labour” inherent in the processes of “knowing” and “marking” a self. This is cultural “work” or work that is not only performed in a professional capacity. The “formation” of the self in the medical Bildungsroman is thus not only determined by professional “work”, like the classical novelistic variant where, as Moretti has illustrated, “formation-socialization” takes place outside the “world of work” (The Way of the World 25). The next section will examine the theoretical contexts surrounding this “cultural work” performed by the narrators of the medical Bildungsroman.

(ii) Work, Technology and Social “Roles”: Chris Shilling in The Body in Culture, Technology and Society, defines “body work” as those set of unofficial tasks performed by an individual to maintain the viability of his/her embodied self within the waged labour environment (73). Work is the primary marker of identity in the medical Bildungsroman, where youth (experiences narrated from the medical residency) is circumscribed by the physical rigor of professional “work”, presented in the narrative as the labouring, cosmopolitan body that the physician/narrator strives to fashion. The physician’s individual, cosmopolitan labouring body is often set apart from others’ in the
narrative, to promote a greater degree of identification for the professionally “marked” body. Chris Shilling defines “cultural body work”, as those forms of presentation developed by a group that allow individual members to recognize “safe” and “familiar” others or “strangers” who pose a threat to their existence and lifestyle (The Body in Culture77). As Shilling has argued, the body often functions as a location for communal norms and this helps determine how an individual intervenes in his/her environment (The Body in Culture76). The physician’s labouring cosmopolitan self is embodied in its interactions with other bodies that are similarly marked. Work, as Shilling argues, is in the process of becoming a “project” – something that is “to be pieced together in increasingly contingent and creative ways” (The Body in Culture85). The doctor-body presented in the medical Bildungsroman, also seeks to reinstate the status and relevance of “expertise” that the novice journeys towards, threatened as it is, by the pace of technological advancement and the ineffectuality of current medical practice against disease and illness. As argued in the previous section, the doctor-narrator performs “informational” labour through the incorporation of “immutable” or “combinalbe” mobiles in the form of particular narratives of patients. Also, as demonstrated earlier, this is significant in the doctor-narrator’s acquiring of “diagnostic agency”, seen to be in a state of decline in the face of technological diagnostic procedures that are wielded by a diverse and diffuse group of actors.

Technology is thus recruited by the doctor-narrator into a social role – it is made into a prosthesis for the doctor-body, who integrates stories about/of his/her patients with institutional records to improvise a new role. As Shilling has argued, a “prosthetic identity” does not refer to any mechanistic device that supplements the body, but has historically denoted artificial body parts that possess a restorative function (The Body in
A prosthetic device or prosthetic technologies thus, restore rather than extend a person’s capacities. The doctor-body in the medical Bildungsroman, restores the viability of the doctor’s role by eliding the technological (the institutional apparatuses that made compiling information possible) and offers in its place, an “expert” doctor-body as the point at which the institutional and social contexts of the individual come to bear on the diagnosis of illness.

Writing about the transcendence of bodily boundaries sought by humans through technological mediation, Shilling argues that these boundaries are neither arbitrary nor limitless. Instead, he suggests, “there tends to be a certain homology between people’s existing bodily capacities and projects, and the types of physical development planned and achieved by humans” (The Body in Culture). Shilling suggests that technology cannot be viewed as being imposed upon a body externally, without any regard for the “realities” of that bodily being. Instead, technology must be viewed as being “integrally related to people’s plans, purposes and capacities. The body in short, remains an important source of technological development” (The Body in Culture). Like the doctor-narrator’s “social role”, achieved through the addition of an “ethical” aspect to the patient’s narrative case history as seen earlier and through the deployment of technology in a socially viable manner, the patient or the ailing body is also seen to aspire to a particular “role”. These “roles” are significant for the “socializing” of identities constructed by narrators in the medical Bildungsroman.

Writing about the practice of “caring” for or “cultivating” the self in Greek culture in his The Care of the Self, Michel Foucault emphasizes the increased correlation of this tradition with medical practice and thought (54). This correlation drew from the belief at the time that afflictions of the body could have an impact on the soul and
similarly, a lack of attention to the “bad habits” of the soul could result in physical misery. Foucault notes the increasing medical coloration of the practice of “improving” or cultivating the soul that the Greeks sought in Philosophy, where even the Philosophers’ School espoused the interconnectedness of education and caring for oneself (55). The patient memoir is an instantiation of such an interconnected education – where caring for the self, also entails learning or educating oneself about aspects of or “roles” required to be assumed by the patient’s ill-self. Foucault emphasizes in his examination of evolution of the practices of caring for the self, the recognition of dependency and needing assistance. He stresses therefore the importance of recognizing the self as “one who suffers from certain ills and who needs to have them treated, either by oneself or someone who has the necessary competence”, rather than simply constructing an image of one who is imperfect and ignorant and therefore requires improvement, correction and training (57). Self-knowledge, or recognizing the need for assistance (medical and filial), is thus of paramount importance in the practice of caring for or cultivating the self.

The performance of illness in the patient memoir is also about laying claim to the socially sanctioned “role” of being ill. Talcott Parsons in The Social System identifies illness as being one of the sanctioned or “conditionally” legitimized modes of “deviance” in a society. The sick individual’s claim to be cared for is made subject to the admission by this individual, that “it would be a good thing to get well as expeditiously as possible” (291). It is “institutionally” mandated that a person who is sick seek treatment from a trained medical professional and be discharged from the duties of his daily life (depending upon the severity and length of his illness), only on the condition that he/she will take on the “sick role”. The implication within the sanction for such “deviance”, is that a certain level of disability and the obligation to get well be accepted by the person
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granted this role. The “deviance” of ailment, is thus controlled through an institutionalized definition of the steps to be taken in the case of illness – seeking professional medical help, being in a state that requires the help of others and accepting that a speedy recovery from illness is necessary. While the patient’s status as such is sanctioned socially and institutionally, he/she is bound by the “moral imperative” to return to a state of health and activity.

Talcott Parsons describes illness as being predominantly a withdrawal into a “dependent relation”, where the person who is ill uses the disability brought on by illness as a basis for legitimizing his/her claim to be “taken care of” (285). Moreover, when a conditional legitimacy is offered to a “deviant” pattern like illness, it automatically shifts, he argues, from an individual to a collective phenomenon. The conditionally sanctioned legitimacy to be “ill” is reciprocally legitimized by the medical professional – who is authorized to provide counsel, treatment and seek payment for the restitution of the ill. Together, thus, the “patient” and medical professional constitute a collectivity that forms a sub-system within the social system. Parsons also identifies the significance of family for the “sick role”, in serving as the structure of support. The partial legitimation of the condition of being sick situates the sick individual in a relationship of dependence with other non-sick individuals, like his family and the medical practitioner and his personal circle, rather than with other similarly “deviant” sick individuals (312). The condition of being ill and its treatment thus gives rise to questions of particular “social roles” not only for the individual, but for the collective. These “institutionally” sanctioned “roles” are also significant in constituting ideas of “normacy” and “deviance”. The next section will examine theories surrounding the construction of “ideal” and “pathologized” identities in
narratives of illness and disease and their contribution to the “normalizing” or “pathologizing” of the individual in the public sphere.

(iii) The “Spectacle” of the Diseased Body and Pathologized Identities: In her critique of Habermas’s universalized formulation of the “Public Sphere”, Nancy Fraser argues in her “Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy”, that a public sphere is not only an arena for the formation of discursive opinion but is an arena meant for the enactment and formation of social identities (68). In addition, public spheres also comprise culturally specific institutions that frame and set the tone of discursive formulation, through the application of specific rhetorical lenses and the filtering and altering of the accommodated utterances. The public sphere may thus accommodate certain expressive modes but exclude some others (69). Moreover, as Ann Travers has argued in her “Parallel Subaltern Feminist Counterpublics in Cyberspace”, the apparent “universality” of the public sphere is characterized by the representation of the subjectivity of an elite group as the “objective category of normalcy” (229). In their visualization of the social “roles” of individuals in the public sphere, the documentaries produced by the Films Division India designate certain categories of “normalcy” and “deviance” through a “gendered” lens. In her How to Have Theory in an Epidemic, for instance, Treichler points to the gendered construction of individuals in AIDS discourse through a representation of the woman as a “passive” or “ineffective” carrier of the virus. This is contingent upon an understanding of the woman as possessing a “rugged” uterus or vagina that is not as easily penetrable or affected by the virus as the “fragile” anus of the man (17). Women are thus viewed as passive recipients of “infection” in the home and embody the “vulnerability” of the home. Similarly, writing about the socially sanctified role of the husband in her Contagious,
Priscilla Wald argues that the “infected man” who brings a disease into the family causes disruption to the “natural (biological) metamorphosis of social roles”, by preventing his daughter/wife from becoming a mother and thus corrupts the institution of marriage (87). The natural/biological roles embodied by the man and woman in the space of the family are thus socially sanctified and are seen to be disrupted via the entry of disease. Moreover, through a designation of the space of the home/family as the socially sanctioned location of reproductive and sexual roles in the medical documentary, the biological and social roles of the female members are conflated and individual rights are replaced or superseded by the rights of the future members of the family.

In her study of foetal photography and pro-life debates in the late twentieth century in America, Carol Stabile argues in her “Shooting the Mother: Foetal Photography and the Politics of Disappearance”, that the ability of visual and reproductive technologies to capture the foetus on film accords this newly discovered terrain a certain degree of autonomy. This “autonomy” is used in the service of the New Right politics (pro-life, anti-abortion crusades), to ideologically transform the female body from a “benevolent, maternal environment into an inhospitable wasteland, at war with the ‘innocent person’ within” (172). These visual technologies, Stabile argues, has effected an erasure of women’s bodies. What is significant about Stabile’s study is the superseding of the rights of the maternal/feminine body and its transference to a newly discovered subject – the foetus, representing and embodying the future of the human race. The medical documentary thus, through a visualizing of the “vulnerability” of reproductive health and the “pregnant” woman, effects an erasure of her body and unveils instead, a deeper, more vulnerable location – the uterus and its biological potential. The
medical documentary also designates certain individual or social identities as “ideal” or “deviant”, as argued earlier in the section on Narrating/ “Storying” Illness/Disease.

Mani Shekhar Singh and Aditya Bharadwaj, in their study of communication strategies utilized by the government of India since the launch of the Universal Immunization Programme (for the eradication of Polio) in “Communicating Immunization: The Mass Media Strategies”, observe that at the level of the family, the government’s communication strategies for immunization in a certain sense had been consciously fashioned to both define and constitute the family (670). The “ideal” healthy family defined by the government’s communication strategies, they argue, was able to simultaneously communicate messages of family planning (by employing images of smaller families with a single child in the service of promoting Pulse Polio Immunization) and presented their particular illustrations of this “model” family as a commonplace one, thereby generalizing this definition of the “ideal” family. The particular instances of a “model” family showed them being responsive to and participating in the State’s programmes and seeking medical care and attention in an ordered manner. Similar to the “model” families observed by Singh and Bharadwaj in the government’s communication strategies for immunization, the Films Division documentaries foreground particular instances of families that are “responsive” to local health initiatives and are “active” in the monitoring of their family’s “health”. The Films Division documentaries also visualize for the viewer, “deviant” bodies in which disease has been allowed to run its course unchecked and such bodies function as “spectacle”. The “spectacle” of the ailing or diseased body, serves to highlight in contrast, “normalized” bodies of “citizens” who ensure a timely medical intervention to check the progress of disease and bodily deterioration.
Craig Hight and Catharine Coleborne’s study of the medical documentary series *Superhuman* in “Robert Winston’s *Superhuman*: Spectacle, Surveillance and Patient Narrative”, has demonstrated that computer graphic imaging provides an “additional layer of spectacle” to the overall aesthetic of the medical documentary (238). Writing about the televising of operations performed on conjoined twins, Jose Van Dijck in “Medical Documentary: Conjoined Twins as Mediated Spectacle” and Catherine Myser and David L. Clark in “‘Fixing’ Katie and Eilish: Medical Documentaries and the Subjection of Conjoined Twins” have argued that the televising of such procedures have taken the place of the 19th century freak show and testify to the continued fascination with extraordinary bodies that continue to be objects of public spectacle. While expert and professional testimony functions within the medical documentary to “pronounce” the presence of illness and provide assurances as to the competence of modern medicine, the “spectacle” of the diseased body is presented to remind viewers of the consequences of bodies that are beyond medical attention. Moreover, as Van Dijck reminds us, viewers are hardly aware of the voyeuristic nature of their examination of these patients’ vulnerable, exposed bodies, presented as they are, within medical scans that legitimize the spectacle (550). The format and content of this popular genre of “hybridized spectacles”, she argues, both “reflect and construct specific norms and values about ‘deviant bodies’” (552).

The medical documentary thus visualizes “normal” and “diseased” bodies, through the incorporation of “individual” stories of patients, expert/professional testimony, computer graphics enabled illustrations of anatomically “correct” bodies and “microscopic” visions of pathogenic invaders. In the process of “visualizing” disease/illness and its treatment however, the medical documentary designates or
“sanctifies” certain gendered social “roles” that supersedes individual rights and constructs specific notions of the “diseased” and “healthy” body. The next section will situate the dissertation within the broader framework of Narrative Medicine and the Medical Humanities.

Section II: Narrative Medicine and the Medical Humanities

This project is located within the larger domain of the Medical Humanities and Narrative Medicine. I will survey in this section, to contextualize these broad areas, M.H. Evans’ detailing of the discipline of Medical Humanities in his “Medical Humanities: Stranger at the Gate, or Long-lost Friend?”, Rita Charon’s definition of the field of “narrative medicine” in her now cult book of the same title and Kathryn Montgomery Hunter’s illustration of the “narrative” features and methods inherent in medical knowledge and practice in her Doctor’s Stories. In addition, I will also detail here, the arguments made by anthropologists and sociologists of medicine, namely Bryan Turner and Vaidehi Ramanathan, who emphasize the centrality of “language” and “discourse” in the experience and treatment of illness/disease. The Medical Humanities is defined by the Literature, Arts and Medicine Database hosted by the New York University School of medicine, as an “interdisciplinary field of humanities, social science and the arts and their application to medical education and practice” (litmed.med.nyu.edu). Research in cultures of medicine in departments of cultural studies and Journals like Literature and Medicine, Journal of the Medical Humanities, New Genetics and Society and Public Understanding of Science, now subjects medicine (from illness memoirs to technologies of medical investigation, from racialized biomedicine to gendered technologies) to discourse
studies. This project does not, however, work with the “medical education” component of the medical humanities. Suzanne Poirier’s work (2002), cited earlier, about the “ethically” limited form of the medical case history and Kathryn Montgomery Hunter’s Doctor’s Stories, about narrative means of enriching medical case histories, are some instances of a now widespread critique of “medical education” and the insistence on a “narrative” awareness in doctors’ clinical practice. The many disciplines that constitute the “interdisciplinarity” of the medical humanities include conventional humanities subjects like history, literature studies, philosophy, fine arts, critical theory, drama, historiography, linguistics, law and theology and religious studies, among others.

M.H. Evans argues that humanities disciplines are especially relevant for addressing the “human” aspects of medicine on account of a) their concern with the interpretation, understanding and recording of individual experience and b) their tendency to pay careful attention to subjectivity and its embeddedness in and reflection of the various interpersonal contexts of society (367 – 368). Evans also proposes four crucial tasks that characterize medical humanities work that are of significance to this project. Firstly, such work makes accessible and illuminates the practice of medicine by providing insights and ideas that are associated distinctively with the Humanities and Social Sciences. Secondly, through the study of pathographies (the act of recording and interpreting the illness experience), such work attempts to foreground the “human side of medicine” and examines the ways in which illness, medicine, suffering, health and disability are experienced. Thirdly, work within the medical humanities attempts to understand the several “subjectivities” articulated within the experience of medicine, illness, health and suffering, in order to make such an understanding transferable so as to
allow us to reflect on the “human condition”. Fourth, such work will utilize aspects of medicine to further enquiry into embodied human nature (369 – 370).

In her now classic *Narrative Medicine*, Rita Charon (who founded the field, initiated the first program in Narrative Medicine at the Columbia University College of physicians and surgeons and holds degrees in Internal Medicine and a PhD in English Literature) attempts to build a “new philosophy of medical knowledge” by identifying the “narrative features” of medicine. Charon argues for the “narratively inflected” nature of medicine and stresses the need to develop the narrative dimensions of the practice of medicine, to bridge the growing divide between doctors and patients. The contextualization of illness, beliefs about mortality, emotional factors that lead to suffering and understanding the aetiology of disease, are some of divides that exist between doctors and patients and can be bridged, she argues, through a shared understanding about disease (39). Developing the narrative dimensions of medical practice can help identify the material and discursive realms of disease as they are ordered by the “story” of an illness. As Charon notes, a disease or symptom that befalls a person is an “event” that is caused by factors that are sometimes identifiable and occurs within a specific time frame and location and has to be narrated to someone from a particular point of view. More significantly, she identifies the singularity of narrative that is conferred upon it by form. The genesis and structure of every narrative is original and irreproducible, in the sense that a narrative creates as it narrates, something that is entirely new, seen for the very first time. The telling of a story of illness thus not merely reports an event that occurred prior to the telling, but produces it (45). Disease is thus actively “produced” in a recounting/telling of an illness experience, thereby encoding specific notions of the body, health and the illness experience itself.
Similarly, writing about the “interpretative” activity of medicine, Kathryn Montgomery Hunter stresses the grounding of this discipline in “subjective knowledge” (xx). The “methodology” of medicine, which comprises the interpretation of the “signs” of disease in an individual patient’s body and the retrospective detailing of the chronology of a particular ailment, she argues, is distinct from other physical sciences. Instead, the “practical knowledge” of physicians is “narratively” structured, in spite of their scientific and technological training and expertise. Hunter too, like Charon, highlights the “narratively inflected” nature of medicine, by harking to the similarities between literature and the medical case history. Literature and the medical case history are similar, Hunter argues, in the attention accorded to the Individual. The medical case history, like literary narrative, comprises instances that embody the collective human experience, while simultaneously testing our generalizations about the individual human (152). More significantly, the “original” and “grounding” data that characterizes medical knowledge and practice, is subjective experience – the individualized practice of medicine in particular contexts by the physician and his/her engagement with others’ subjective accounts of their experience of illness. The “uncontrolled” and unpredictable variables in an individual case can thus be accommodated by narrative and an awareness of this “narrative” structure of medical knowledge makes possible a certain “flexibility” of traditionally “inalterable” clinical rules (155). While Hunter is essentially arguing for a “literary” curriculum for the teaching and practice of medicine, that includes a study of literary fiction, drama and autobiography about the experience and treatment of illness, she has also signalled at the importance of language, discourse and representation in the understanding of disease/illness.
In her *Bodies and Language*, Vaidehi Ramanathan similarly underscores the ways in which language itself and “texts of body matters”, both construct and are constructed by a range of discourses that include societal and biomedical ones. She draws attention to those instances of illness experience where not only the body, but language skills also break down. She thus highlights the “different hues” in narrating illness, where the material conditions of the body and the communities with which one engages become increasingly complex when dealing with specific illnesses like Alzheimer’s (narratives of such patients are broken by moments of “coherence” or “incoherence”), Autism or partial hearing (in both these cases, patients feel trapped in silence on account of being unable to deal with the “languaged” world – the primary means of engaging with the emotional and with other humans). The materiality of the illness experience here, like a debilitating medical condition that prevents one from even carrying out everyday activity, precedes the narration or mediation of the experience through language. As such, Ramanathan argues, the only way an ailing individual can articulate his/her experience of illness, is through the colonizing tropes of medical science (4). The discursive realm of disease is thus arguably more central or pervasive than its material one.

Bryan Turner in his *Body and Society*, has also stressed the discursive and material domains of disease by combining the notions that 1) disease is a language 2) the body is a representation and 3) medicine is a political practice (201). He signals to a “medicalization” of the body and society that is made possible in the context of a secularized society, where religion has been replaced by medicine as the social guardian of morality (203). Official definitions of disease and health and their coercive acceptance form the basis for the professionalization of medicine. Such official definitions enable an identification of the “objectivity” and “reality” of disease entities, which exist outside
Medical science provides criteria for normalcy by drawing upon law and religion, and thus articulates a moral discourse of appropriate behaviour (in terms of lifestyle where the responsible citizen safeguards his/her health through an ascetic adherence to “healthy” habits and the moral deviant through irrational, irresponsible habits, self-induces a state of “unhealth” and thus becomes a burden on the state). Disease, as Turner argues, is neither a unitary concept nor does it signify natural processes. Instead, Turner defines it as a “classification reflecting both material and ideal interests” (214). The “nature” of disease can only be understood when placed within a hierarchy of moral evaluations that are in turn reflective of power in social groups.

The next section will detail the primary texts studied in this dissertation through a brief summary of their content and contexts.

Section III: Primary Texts

Patient Memoirs

Anup Kumar’s The Joy of Cancer tells the story of Kumar’s experience and triumph over lung cancer. Kumar is a postgraduate in nuclear physics and worked in advertising for most of his life. After being diagnosed with cancer in a medical test undertaken before travelling to Abu Dhabi for a job interview, Kumar’s life quickly spirals downwards as he struggles to cope with the demands of his family and dwindling finances. The Joy of Cancer presents for the reader, a “battle plan” to face cancer that weaves together experiences from the author’s life. Kumar’s narrative criticizes the fallibility of medical diagnoses, while simultaneously foregrounding the need to identify
a form of treatment and the kind of physician that is best suited to an individual. The book combines Kumar’s narrative with information about cancer, specialized institutes for its treatment and cure and alternative forms of healing.

Anup Kumar’s *Smiles and Tears: A Salute to Cancer* showcases the real-life stories of cancer survivors. Kumar is the editor of the book, bringing together the “stories” of twenty three other cancer patients and prefacing the book with excerpts from his own story in *The Joy of Cancer*. The narratives in *Smiles and Tears* describe experiences with various types of cancer, including lung cancer, breast cancer, colon cancer, leukaemia, thyroid cancer and colon cancer, among others. Anup Kumar here narrates the story of his battle with cancer and identifies the need to bring together information and advisory about the illness in India and stresses the significance of such narratives for other patients. He describes Indian patients’ reticence to narrate their experience of cancer and argues that “western” patients’ accounts of the illness are “alien” to the Indian experience and treatment of cancer. Narratives of illness in *Smiles and Tears* relate experiences of medical care, chemotherapy, encounters with a community of patients and caregivers and alternative forms of healing.

Anita Jayadevan’s *Malicious Medicine: My Experience with Fraud and Falsehood at Infertility Clinics* is translated from the Malayalam by P K R Warrier and C S Unni. Jayadevan is a school teacher, who, along with her husband, underwent treatment for infertility and attempted to conceive a child with the help of ART procedures. Jayadevan’s memoir reflects on the ethical aspects of Assisted Reproductive Technologies (ART) in India, in addition to detailing the “social” pressures of attaining motherhood and the consequent lure of “treatments” advertised by infertility clinics. Her memoir is a critique of various methods of “treating” infertility via ART procedures like
Artificial Insemination, Intrauterine insemination and In Vitro Fertilization, among others. Jayadevan recounts her experience of various ART procedures at numerous infertility clinics that not only proved futile, but endangered her life.

Lata Mani’s *Interleaves: Ruminations on Illness and Spiritual Life* narrates her experience of permanent transformation after she sustained a head injury from an accidental freeway collision in the United States in 1993. Mani is a noted Indian feminist and historian and taught at the University of California, Davis. Mani’s car was one of six vehicles hit by a stolen Pepsi truck, whose driver was speeding away from police patrol cars and as was discovered subsequently, suffering from depression and engaged in a bid to end his life. Mani sustained a closed-head injury as a result of this accident and was chronically impaired. Her memoir is a testimony of the consequences of her injury, which resulted in a heightened and painful sensitivity to sound, cognitive impairment and a drastic reduction in physical activity and productivity. The structure of *Interleaves* is illustrative of Mani’s transformed cognition, with each chapter of the first section titled “The Journey”, engaging with one single idea or activity like a trip to her garden or the difficulty in “communicating” an experience of illness. Mani testifies to how even a small activity like going to her garden or making her way to the table in her living room for a meal, represented a “challenge” that required hours of preparation.

Yuvraj Singh’s *The Test of My Life* is co-authored with Nishant Arora, Singh’s manager and former cricket correspondent for CNN-IBN and Sharda Ugra, senior editor at ESPNcricinfo, the world’s largest independent website with a single sport focus. The book chronicles Singh’s life from his childhood struggles with an ambitious and exacting father, his first coach, his entry into cricket and stardom through to the first “signs” of his cancer during the 2011 cricket World Cup. Singh recalls “dismissing” the first signs of
ill-health, ascribing them to anxiety and stress owing to the pressures and chaotic schedules of the World Cup matches. He is subsequently diagnosed with a rare form of germ-cell cancer and *The Test of My Life* recreates for the reader, Singh’s acceptance of his condition, his struggle through chemotherapy and his fears and anxieties about being unable to return to being a professional sportsman. As a cricketer, Yuvraj Singh had the support of India’s richest sporting body, the BCCI and this ensured not only that he could afford the best treatment in the world for his condition but offered wide media coverage for his “story” and allowed him to return to playing cricket internationally. Singh’s memoir however, also emphasizes his “individual” will and endurance, in addition to portraying the selfless labours of his primary caregivers in aiding his recovery and “survival”.

Russi M. Lala’s *Celebration of the Cells: Letters from a Cancer Survivor* is written in the form of letters addressed to “Vandana”, a fellow cancer patient. Lala is a journalist, was the manager of the first Indian book publishing house in London and is well known for his chronicles of the Tata heritage in India. Each letter in his book comprises a chapter and each deals with the central issues of living with cancer, buttressed by Lala’s own experiential wisdom. While Lala himself is diagnosed with non-Hodgkin’s lymphoma, his addressee Vandana, is a Hodgkin’s lymphoma patient. Through Lala’s letters to Vandana, the reader learns of his experience of becoming diagnosed with cancer, his struggle to cope with the pressures of work while undergoing chemotherapy and the effects of his illness induced dependency on his wife. In addition, Lala also counsels Vandana and by extension, the reader, on the various aspects of his particular form of cancer and the various socio-cultural coping mechanisms that once can “learn” to overcome the transformation brought on by illness. Lala testifies to instances
from his own life where he transforms his social interactions, expectations, ambitions and
daily routine, to set a new standard of “normalcy” inflected by the effect of chronic illness.

**Doctor Memoirs**

Abraham Verghese’s *My Own Country* tells the story of an epidemiologist’s struggle to cope with the outbreak of AIDS in America in the 80’s. Verghese is Professor of Medicine and Chief of Infectious Diseases at Texas Tech Health Sciences Center, El Paso. *My Own Country* narrates the author’s experiences with treating AIDS patients in the rural town of Tennessee, at a time in America when AIDS was still believed to be an “urban” disease and treatment and cure were highly stigmatized. Varghese’s story puts together the stories of his many patients, alongside a story of the AIDS virus itself and the trajectory of its arrival in America and the town of Tennessee. Over the course of the narrative, Varghese’s life increasingly mirrors the status of his patients – he feels alienated and helpless in the face of what appears to be a losing battle against a deadly virus.

Noshir H. Antia’s *A Life of Change: The Autobiography of a Doctor* narrates the story of Antia from his modest beginnings in Hubli, Karnataka, to becoming the famous founder of one of the earliest burn units at Mumbai’s JJ Hospital, the Foundation for Research in Community Health and the Foundation for Medical Research. Antia narrates his experiences at Grant Medical College, his nine years of service in Britain’s hospitals during WW II and the inspiration behind his choice of specialty. Although located within the traditions of modern medicine, Antia warns against the technologization of medicine and criticizes medicine’s current emphasis on expensive tests and super specialties to
diagnose even the simplest of medical conditions. Drawing from his experiences of working in small hospitals with limited resources and rural health initiatives, Antia attempts to demonstrate how cost-effective and simple medicine can also be effective.

Atul Gawande’s *Complications: Notes From the Life of a Young Surgeon* is his first book and draws from his experience as a surgical resident and brings together key “moments” from that eight year training period. Gawande is a 2006 MacArthur Fellow and a General Surgeon at the Brigham and Women’s Hospital, Boston. *Complications* offers an insider’s view of medical practice and narrates incidents from the author’s life and borrows “stories” from other doctors to tell the story of an “imperfect science”. While Gawande focuses on the fallibility of physicians, the dilemmas and uncertainties of practical medicine, he constantly foregrounds the little understood “extraordinariness” of medicine. Gawande examines a variety of subjects, while narrating his own experience of treating illness and working in a medical institution, that range from fatal errors made by doctors, mysteries and unknowns in medicine to what it takes to make a “good” doctor.

Sandeep Jauhar’s *Intern: A Doctor’s Initiation* tells the story of Jauhar’s experience of a gruelling residency at a New York Hospital. Jauhar, now a practicing Cardiologist and Director of the Heart Failure Program at Long Island Jewish Medical Center, recounts his initiation into the medical profession, positioning his story as one that will be both instructive and inspiring to aspiring doctors and will simultaneously work to dispel the popular myth that doctors are “Type A overachievers with little self-doubt” (xv). The book chronicles Jauhar’s crisis and doubt as he enters medical school after spending years training as a physicist. Jauhar struggles to find his footing at the prestigious New York Hospital, where the rigors of residency are markedly different from his earlier, more sedate, professional life. Over the period of a three year residency,
leading up to a fellowship in Cardiology, Jauhar narrates his feelings of scepticism, self-doubt and eventual triumph at surviving residency and pride at having attained membership into an elite profession.

The Films Division Medical Documentaries

The Films Division India, part of the Ministry of Information and Broadcasting is the main film-medium organization of the Indian Government. Established in 1948, the Films Division both produces and aids freelance and in-house filmmakers to create and distribute films that record social, political and cultural realities and events in the country. Under the category of “Health”, the Films Division, often in association with other medical/scientific research institutes in the country, produces documentary films and “shorts” (two or three minute public interest messages about various health and sanitation issues) that are intended to spread awareness about various diseases and illnesses. The Films Division documentaries are telecast on national and local television networks, in addition to being available to the public for sale in their distribution offices, as screenings in film festivals and various cinema houses in the country and boasts an audience of about ninety to a hundred million per week (Filmsdivision.org). This dissertation studies several medical documentaries produced and distributed by the Films Division in the late twentieth century and I will offer here a brief summary of the main documentaries under study.

integrate images of patients’ bodies in varying stages of disease/illness and also present fictionalized stories of individuals’ lives affected by disease. *Cancer*, for instance, directed by C.K.M. Rao and winner of the National Film Award in 1997 in the category “Best Scientific Film”, integrates several “individual” stories as part of its narrative. The film presents several tobacco users who exhibit visible malignant “growths” and directly address the viewer to testify to the harmful effects of their prolonged tobacco consumption. *Gita Ki Kahani* and *Your Enemy -TB*, in addition to focusing on several such “cases” where the effects of disease are “visible” on the body, also primarily revolve around fictionalized “stories” of the effect of TB and Hepatitis B respectively. *Your Enemy-TB* focuses on a fictionalized representation of a couple, “Mala” and “Gopal”, meant to represent the average Indian couple who are vulnerable to infection by TB and *Gita Ki Kahani* narrates “Gita’s” experience of being diagnosed with Hepatitis B and “stages” the various problems and anxieties she faces, as a result of her infection through the virus.

In addition, the Films Division medical documentaries also inform the viewer about the government’s efforts at preventing disease and hail the advances made by medical science, instructing viewers to seek remedy and diagnosis for any “signs” of ill-health immediately. “Early detection” is emphasized by the narrators of these documentaries, sometimes portrayed as a disembodied voice that contextualizes the images and “stories” on screen and often as an expert, “professional” health care worker. Doctors and researchers are also integrated into the narrative, through “comments” about the particular disease/illness recorded at their place of work, emphasizing their institutional affiliation and authority. Medical documentaries like *Controlling Leprosy* (1989), *AIDS* (1995), *Preventing Anaemia through Nutrition* (1994), *H1N1 Flu: Few
Facts (2010) and Health for All (1982) focus on the government’s efforts at eradicating disease and ensuring a wide distribution of treatment and diagnostic centres. In addition, these films involve a direct address by doctors/experts (sometimes an actor/narrator who dons a white coat to symbolize expertise and also “real-life” doctors whose names and affiliations testify to their professional authority) who urge the viewer to “monitor” themselves and their families and ensure a “timely” medical intervention. The Films Division documentaries cited above, also instruct viewers about what determines a “healthy” and “ailing” body and visualize the ways in which such bodies can be identified.

The next section will defend the time frame of the project and offer the major cultural contexts that underpin and contribute to the relevance of the texts examined in this dissertation.

Section IV: Time Frame/Rationale

As argued earlier, narratives of disease organize viewers’/readers’ perception of the various aspects of the “reality” of disease. Our interpretation or understanding of the experience of illness and its treatment is governed by a “cultural imaginary” framed around disease. This “cultural imaginary” informs and is informed by the various non-fictional accounts of illness experience and its treatment examined in this study. In addition to memoirs by doctors and patients and medical documentaries produced by the Films Division, India, the “cultural imaginary” that determines information about and perceptions and definitions of disease, is also influenced by popular fictions about disease and epidemics, State authorized medical and public health discourse and media reports on
“scientific” research about disease. Rodale Inc.’s *Men’s Health* and *Women’s Health* magazine launched via the India Today Group, Apollo Hospital’s *B Positive* magazine, *Healthy-India.org*, a web resource for matters of healthcare and disease prevention launched by the Public Health Foundation of India and the Ministry of Health and Family Welfare, Government of India and the regular science and technology and health columns and features in major English dailies like *The Hindu* and *The Times of India* are a few major popular instances of medical and health discourse in the public domain in India.

This study of doctor and patient memoirs as an instance of the medical *Bildungsroman* and the narrative ordering of an experience of illness and its treatment in these memoirs and the medical documentary, are thus located within the “cultural imaginary of disease”. My focus in this dissertation is on doctor and patient memoirs and films division documentaries produced in the late twentieth century and this section provides two main contexts to justify the chosen genres/texts. The first is the rising popularity of the “memoir”, which characterizes the present-day cultural moment in the U.S and U.K. This, along with the related rise in the culture of “publicly” sharing a private experience like illness can be used, in the context of India in the late twentieth century, to understand a culture of publishing and reading “stories” about an experience of illness and its treatment. Commenting about the history of the memoir and reviewing Ben Yagoda’s (2009) book on the subject, for instance, Daniel Mendelsohn notes that the genre’s popularity in our contemporary time should be viewed alongside the parallel rise in the popularity of the reality show, the use of cell phones and internet publishing, that now blur the lines between “real” and “artificial” and “private” and “public” (2010). These related phenomena have set the tone in the late twentieth century, for a culture of self-exposure and self-discussion on which the popularity of the memoir depends.
Mendelsohn via Yagoda, likens the memoir boom in the seventeenth century, caused by the rise in printing technology and paper production that accelerated the scale of publishing, to the current explosion of the personal narrative genre, similarly fuelled by the advances in media and distribution (microblogging and social networking platforms).

Journals like *Biography, Auto/Biography Studies* and *The Journal of Medical Biography, Slate* Magazine observing a “Memoir Week” from 30 March 2007, with invited pieces from prominent memoirists and critics of the genre focusing on the difficulties, history and appeal of the genre, are significant instances of the rise in academic and popular interest in the personal narrative in our contemporary times. The second is the existence of a “social literacy” of disease and the increase in the “public critique” of medical practice by doctors and patients.

(a) The Memoir

In her “But Enough about Me, What Do You Think of My Memoir”, Nancy Miller challenges the charges of “narcissism” and terminal “moi-ism” levelled against the contemporary memoir, which she defines as the “most important narrative mode of our contemporary culture” and reads it instead as an encounter with the “other” (422-23). The “memoir craze”, Miller argues, can be productively understood as the “hunger” for a “narrative” through which one can make sense of his/her past. Unlike the novel, the biography and other prose forms including the reader’s own unrecorded history, all of which rely on a measure of “identification”, the memoir cannot do without it. The memoir for Miller initiates a “process” of remembrance, where the “reading” of a memoir is an “interaction” between the reader and the memoir as a screen, that “prompts” memory construction itself (“But Enough About Me” 427). Moving this “craze” out of a
distinctly American context, Miller identifies the popularity of this genre as being about its ability to function as “prosthesis” or “aid” to cultural memory (“But Enough About Me” 432).

Similarly, writing about the “booming” industry of the memoir, in his *Introduction: Disability and Life Writing*, Thomas Couser notes that this popularity of writing about the “self” is not a first of its kind phenomena, but is still one that surpasses any other in literary history in terms of scale. With specific reference to recounting or “testifying” to a condition of being ill or treating the ailing, as argued earlier via Arthur Frank, the “authority” and “appeal” of narratives about illness and disease are rooted in the belief that “truth” is produced by the body at the extremes of suffering (“The Rhetoric of Self-Change” 48). The “cultural imaginary” that frames the doctor and patient memoirs and medical documentaries under study in this dissertation, can also be contextualized within a rise in the “sharing” of a private experience and its initiation of a “process” of remembrance. Memoirs written by doctors and patients and the medical documentary, as seen earlier, are about encountering an “other” in various ways. These narratives are “relational” – doctors rely on the “accounts” of patients to build a “case history”, patients rely on the accounts of “carers” to render their ailing selves “familiar” and the documentary relies on individual “stories” of illness and testimony to “sentimentalize” illness/disease for the viewer. This is therefore a study of a “rise” in the culture of *narrating* an account of experiencing/treating illness, so as to “organize” the ways in which readers/viewers make “sense” of their own vulnerability/experiences of illness/experiences of encountering medical science. The doctor and patient memoirs and medical documentaries under study thus reflect an emerging culture in India, of initiating a process of “remembering” through narrating and “interacting” with narratives of others.
These texts provide a way of engaging with our experience of illness, its treatment and the transformation it generates in our interactions with others in society. They offer a means of “constructing” our very memory of a chaotic experience like illness and its management, very often dispersed amongst a diverse group of actors, social contexts and causes. While the recording of an experience of illness is by no means a new phenomenon, as Michael Bury (“Chronic Illness”) and Kathryn Montgomery Hunter have noted, it is only recently, with the rise in “chronic” illness and the “lengthening” of human life made possible by advances in medical science, that stories about the “individual’s” experience and examination of illness been written/made possible.

Hunter has noted the rising “particularization” of widespread experiences like illness, through “individual” stories about the experience of organ transplantation, serious illness, hospital crisis and obscure medical cases in an array of genres like television drama, fiction, autobiography and media reportage. However, Hunter also emphasizes the importance of these “medical narratives” in enabling us to think about our lack of control, the limits to our autonomy, the threat of extinction and our attitudes towards chance, choice and authority. It is thus significant that Hunter likens the contemporary illness narrative in American culture, to a “midlife version of the growing up novel” (153). Here, Hunter argues, the author and hero-narrator merge into one figure, in an “autobiographical (or autobiographically fictional) account of an individual’s growth in circumstances not of his or her own choosing” (153). Thus, in our contemporary age of the “memoir craze”, the Bildungsroman emerges as a form of life writing popular among those writing about their engagement with illness and its treatment. The significance of this “growing up novel” and its cultural manifestation as an account of “growing”, in an unforeseen circumstance of experiencing and healing illness, lies in its functionality for
narrators experiencing anxieties about “choice”, “authority”, “control” and “autonomy”.
As noted earlier via Joseph Slaughter, the modern *Bildungsroman* is characterized by an individual’s struggle to attain “fixity” for his/her “self”. Any restriction to the resistance to oppression and security, property and liberty, tend to limit an individual’s ability to attain “fixity”. The self’s “fixity” is dependent, in the modern *Bildungsroman*, on an ability to narrate one’s story (Slaughter, 412). The modern *Bildungsroman* and the medical *Bildungsroman* in particular, give rise to questions of agency and voice, the second context for the present study.

(b) A “Social Literacy” of Disease and a “Public Critique” of Medical Science

Hunter, as seen earlier, has postulated that personal stories of illness have attained a great prominence in the late twentieth century. In addition, Hunter also illustrates how issues of health-care policy are debated and their meaning negotiated in legal terms, not in abstraction as “public policy”, but as “individual cases”. She argues that it is the names of “individuals” that come to stand for particular issues and their resolution. Most notable among her several illustrations of such “individuals” who represent health care issues is Dax Cowart, victim of a propane gas explosion which left him severely disfigured and disabled and his “fight” to resist the “violence” of his medical treatment/rehabilitation. Cowart became symbolic of the patient’s autonomy with his widely publicized consistent refusal of medical treatment, carried out against his wishes, and the pain and violence of the “medical” efforts to prolong his life. Such medical “cases” that are “particularized” in their association with an “individual” abound in India in the late twentieth century.
Two of the patient memoirs being studied here for instance, Anita Jayadevan’s *Malicious Medicine: My Experience with Fraud and Falsehood at Infertility Clinics* and Yuvraj Singh’s *The Test of My Life*, are instances of a particularization of a widespread experience. In the case of Jayadevan, who testifies in her memoir to the filing of over two thousand representations to the Supreme Court and their culmination in the passing of the ART (Regulation) Bill & Rules, 2008, her real-life “struggles” with unregulated and erroneous reproductive technologies, converge with the hero-narrator of her “story”, to become symbolic of the ethics of practicing such procedures in the country. Yuvraj Singh’s memoir, chronicling his experience of a rare form of cancer that threatened his life and career and his cancer support group YOUWECAN, symbolize the “heroism” of cancer survivors. YOUWECAN’s website for instance, collapses the figure of Singh with the organization’s mission, through the tag in the section detailing his “story” that reads “Yuvi can”, thereby stressing the links between Singh’s particular experience and survival and the transferability of his (widely publicized) experience with other cancer patients. More recently, the widely publicized case of Anuradha and Kunal Saha in India became symbolic of medical malpractice suits and the patient and caregiver’s “rights”. Anuradha Saha, an Indian-American child psychologist, did not receive appropriate treatment from doctors at the Advanced Medical Research Institute, Kolkata who failed to diagnose her affliction from the rare disease, toxic epidermal necrolysis. Anuradha Saha subsequently died as a result of incorrect diagnosis and the administering of a steroid overdose by her doctors. Kunal Saha, Anuradha’s husband and a doctor specializing in HIV/AIDS, waged a fifteen year legal battle with three doctors responsible for his wife’s incorrect diagnosis and death and the AMRI hospital, which culminated in the highest ever compensation (5.96 crore rupees) awarded by the Supreme
Court of India in a medical negligence case. Media reports about Kunal Saha’s legal battle, significantly emphasized his “persistence” and the “precedents” set by his example that urged “others” to speak up against medical negligence and was seen as defining the medical professional’s “mission” in our society, in addition to raising the “value of human life” in India (“In Support of Patient Rights”; “NRI Doctor Wins Record Medical Negligence Payout”).

These particularized stories of illness, survival and medical negligence, in addition to sporting a human face with an “individual” story, are also seen as “representative” of a larger collective. “Individual” stories of triumph and resilience are also significant in their emphasis on the “social” or “community”. For instance, writing about his legal battle and the “historic” Supreme Court compensation awarded to him, Kunal Saha writes in an Outlook India piece that his efforts to bring justice for his wife’s death and his establishment of PBT (People for Better Treatment, a non-profit organization set up for patients’ rights), was to ensure that “other Anuradhas” may get a chance to enjoy life (“End the Omerta of the Lambs”). Personal stories of the ill, thus, play an important role in our contemporary era. As argued earlier via Michael Bury, the “grand narrative” of biomedicine has given way to the patient’s right to speak about his/her individual experience of illness and his/ability to express scepticism about medical care/cure (“Illness Narratives”). As chapter two will demonstrate, patients “perform” the labour of acquiring “expertise” and are located in a social network of disease literacy.

As chapter three on the doctor memoir will demonstrate, doctors also articulate an anxiety about the shortcomings of medical practice and perform a “social” role through the voicing of their critique. Several of the doctor writers studied in this dissertation,
namely, Sandeep Jauhar, Abraham Verghese and Atul Gawande, are regular contributors to major newspapers and magazines. Verghese’s articles, for instance, have appeared in the *San Francisco Chronicle, Wall Street Journal, Texas Monthly, Outlook India, the New Yorker* and the *New York Times*, engaging issues about the doctor’s bedside manners, narrating individual “stories” of patients, medical education and the practice of modern medicine. Gawande has been a staff writer for the *New Yorker* since 1998, having been recognized for his “insider’s view” of surgical residency in his early writings about the life of a surgical resident in *Slate* magazine. Jauhar has similarly contributed to *Slate* and the *New York Times*. The most notable of his writings is his critique of the “night float” system (where medical residents work exclusively night shifts for a certain period of time, meant to replace an earlier system of interns and residents working up to 36 hours at a stretch) in “When Rules for Better Care Exact Their Own Cost” (1999), published in the *New York Times* during his medical residency.

These doctors testify to the “controversial” nature of their critique of medical practice, both within their place of work and outside, where journalistic writing during residency has resulted in conflict within the workplace. Jauhar for instance, testifies to his article on the “night float” system causing a “firestorm” at his hospital, resulting in a meeting of the medical board which feared that he had created a “liability risk” (163). Gawande similarly recalls asking for “permission” from the chairman of surgery at the hospital where he was a resident, before publishing an article about doctors making mistakes (xiii). Although these doctor writers rely on a certain degree of professional and textual (afforded by the autobiographical form) authority to “write” about their experiences of healing/treating illness and to voice their critique of medical education and practice, they also contribute to the “opinion” pages and columns of popular newspapers
and magazines in a “social” role. While the doctor voices his critique from within the medical institution, he/she is speaking in a public forum from a wider socio-cultural location that transcends the professional. The testimonies provided by these writers about the feared “backlash” from their articles in the public media and their “risky” choices of exposing “errors” in their own places of work and about their own professional practice, is an instance of “transcending” a professional identity and moving towards a more “social” identity.

Doctors’ contributions to the open page of The Hindu, a feature that has attained regularity since 2011, are a significant instance of the developing of a “socialized” identity by medical professionals in India in recent times. These contributions are often followed by a brief biography of the contributor that cites his/her specialty and institutional affiliation, providing the professional “authority” underpinning these pieces. Their content however, is a non-specialized or non-academic address to the general public about the issues that plague healthcare, medical education and practice in India, in addition to personal accounts about their patients, advice about the management of disease/illness or “real-life” instances that serve as the germ for the ideas developed in these articles. The study of the doctor’s development of a “socialized” identity, through a condition of treating/encountering disease, is thus located within this contemporary tradition of “voicing” a personalized/individualized account of experiencing medical education and practice and the public “sharing” of this experience.

The next section will provide a brief overview the organization of the thesis.
Section V: Organization

This dissertation consists of seven chapters, organized around three main sections, to study the narrative ordering of illness/disease at the level of the Individual, the Filial and the Social. I will now proceed to a summary of individual chapters.

The Introduction sets out the aim and scope of the dissertation, surveys its theoretical contexts, namely narrative and cultural studies of medicine and the representational turn in studies about disease/illness. The scope and aim of the dissertation, as seen in this introductory chapter, addresses questions about the importance and relevance of studying non-fictional accounts of disease/illness in the late twentieth century. In addition, this chapter has presented brief summaries of the primary texts studied – doctor and patient memoirs and medical documentaries of the Films Division, India.

The First Section of the Dissertation titled “Illness, Healing and the Individual” comprises two chapters, chapter two on the patient memoir and chapter three on the doctor memoir. Chapter two will examine the recounting of a particularized “story” of the corporeal experience of illness, at the level of the Individual in the patient memoir. This “story” takes the form of a medical Bildungsroman, particularly, the Bildungsroman of suffering, where the patient-narrator charts his/her movement through the various institutionally governed roles of “patient” (at the moment of medical diagnosis), “dependent” (recognizing the need for care) and “convalescent” (through a recognition of the necessity to improve and return to a condition of “health” and socio-cultural “productivity”), occasioned by the onset of illness.

The third chapter of this dissertation studies the doctor memoir or the Bildungsroman of healing, which charts the development and transformation of the
doctor from novice “trainee” to “professional”. The period of “youth” in the Bildungsroman of healing or the doctor’s “novice” self, is finite and must eventually give way to “maturity” and expertise. The doctor’s Bildungsroman of healing marks a shift from the individual, “novice” self to the social/expert self, with the filial/familial intervening. This chapter will study the Bildungsroman of healing at the level of the Individual. This chapter anticipates the next section of the dissertation, “Towards the Social”. This next section, Section B, comprises chapter four titled “Filiation and Affiliation: The Contexts of Illness and Healing”.

The fourth chapter will study filial connections in the doctor memoir, the patient memoir and the representation of the “filial body” in the medical documentary. This chapter will examine the doctor-narrator’s transcendence of his/her filial networks which comprise, in addition to the family, the passively acquired education during the period of “training” and the treatment of individual cases within the medical institution, where this narrator has a small or no measure of agency. I will also examine here the construction of a “filial-self” in the patient memoir that recognizes the dependence on filial networks of care and performs the “labour” of improvement that is seen as being “owed” to his/her network of carers. The “filial body” in the medical documentary similarly visualizes, via a sentimental or affective narrative, the filial networks of care that the individual body is embedded in. This chapter will examine how the “filial body” is visualized in the medical documentary – this body is seen simultaneously as requiring care and as posing the threat of infection/contagion. I will now move on the final section of the dissertation, “The Social” which comprises Chapters Five and Six.

Chapter five titled “‘The Doctor is IN’ ”: Community and the Doctor Memoir”, addresses the doctor-narrator’s framing of his individual, labouring self as relevant for
the community, in addition to focusing on the emergence of a “social self” in the doctor memoir or the *Bildungsroman* of healing. The “Expert” and “Social” self in the doctor memoir, is a culmination of the arc of development initiated by the doctor-narrator, where his/her individualized “story” and identity are “socialized”. The doctor-narrator’s “expert” self is socialized through certain agential moves – namely, through the voicing of a moral discourse in the text, through an engagement with the global/general contexts of medical practice while being rooted in the particular/filial and the articulation of a critique of medical practice.

Chapter Six titled “Disease, Prophylaxis and the Narrative Society” will study the construction of a “narrative society” by doctor-narrators, via James Dawes’ formulation that a narrative society conceptualizes society and people as “narrative” rather than through “narrative”. I will also examine here the pathologization of the body in the medical documentary, where disease/illness in particular instances, is made relevant in a general context. In addition, this chapter will also study the sentimental narrative in the medical documentary, which works through the forging of affective links for the viewer between the individual body visualized on-screen and the spaces inhabited by this body, and by extension all bodies, at the level of the individual, family and community.

The representation of the “filial body” in the medical documentary has been examined earlier in chapter four on filiation and affiliation. This chapter will focus on the forging of affective links in the medical documentary at the level of the individual and the community. In my final and seventh chapter, I sum up the key arguments of the preceding chapters.
Works Cited


*Health For All.* Dir. Y.N. Engineer. B.N. Mehra. Films Division Productions, 1982. Film.


*Sexually Transmitted Diseases*. Dir. B.G. Devare. B.G. Devare, 1982. Film.


*There is Life For Selvi.* Dir. K. Jagjivan Ram. Films Division Productions, 2004. Film.


